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editorial

The impairment conundrum

Shortly after I became Editor of this magazine, a fellow journalist suggested that, in referring to how we, as disabled people with a variety of impairments work together, I might have indulged in what they referred to as “impairment-based, medical model journalism”. My somewhat testy response to that was, well, if we can’t talk about our impairments, who can.

That’s a position which I continue to entirely stand by. However, it does not imply open season on the discussion of impairments and conditions by anyone. We must be constantly alive to the readiness by non-disabled people to ask us about intimate areas of our being with which they have no business. Many of them remain as far away from the concept or the reality of the social model of disability – that it’s barriers not impairments which disable us – as it’s possible to be.

This is an issue which has been brought into sharp focus recently, not least because this month’s issue carries two pieces about different parts of the relationship of disabled

people to health service delivery. In both cases, the discussion is clearly contextualised in the warp and weft of the social model.

“The chief danger is that people fix on impairment rather than either on us as people, or the external factors which truly disable us”

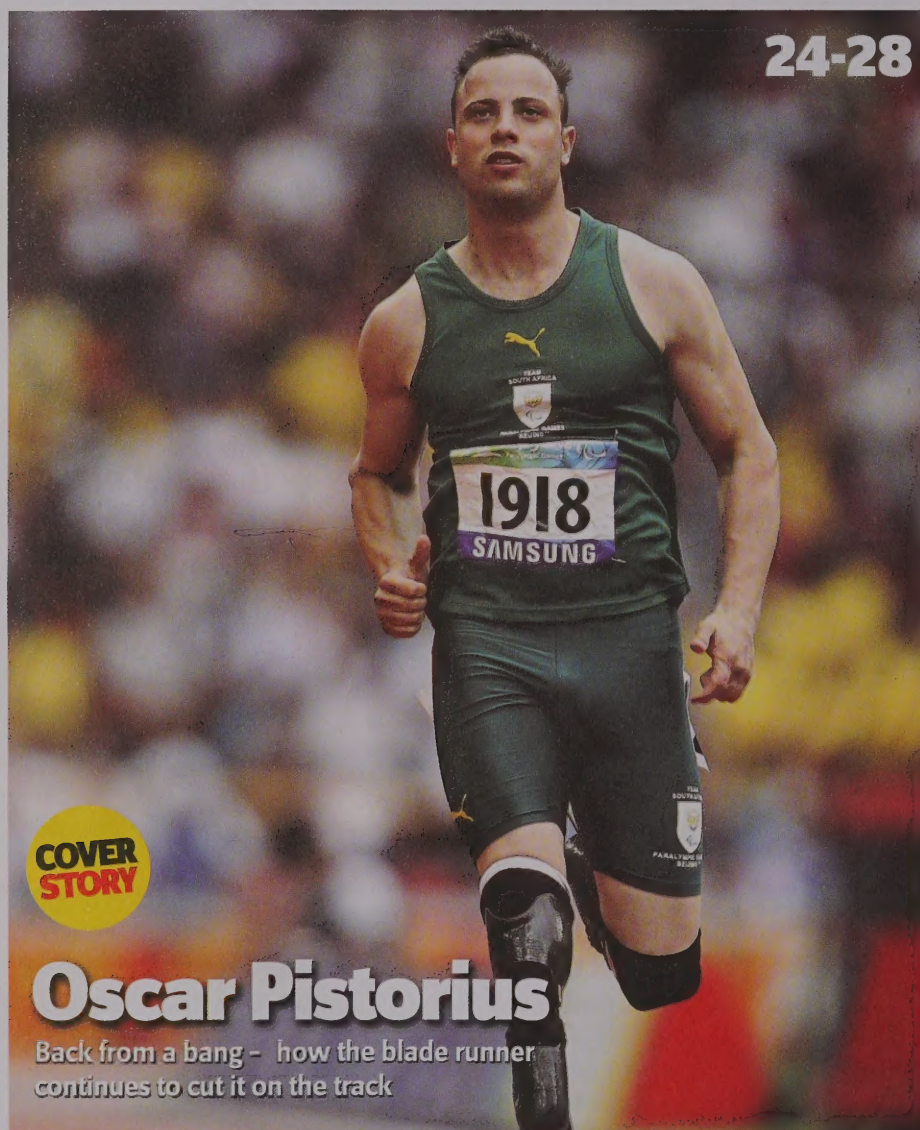
Elsewhere I was asked to join a group set up to monitor production of a TV series involving disabled people. At the first meeting, prospective contributors were talked about in deeply medicalised terms.

Personal matters aside, the chief danger is that people fix on our impairment rather than either on us as people, or the external factors which truly disable us.

So while we, as a community, definitely feel that impairments are as much part of us as colour of skin is to others, we must always beware of gratifying the morbid, the ghoulish or the inappropriate.

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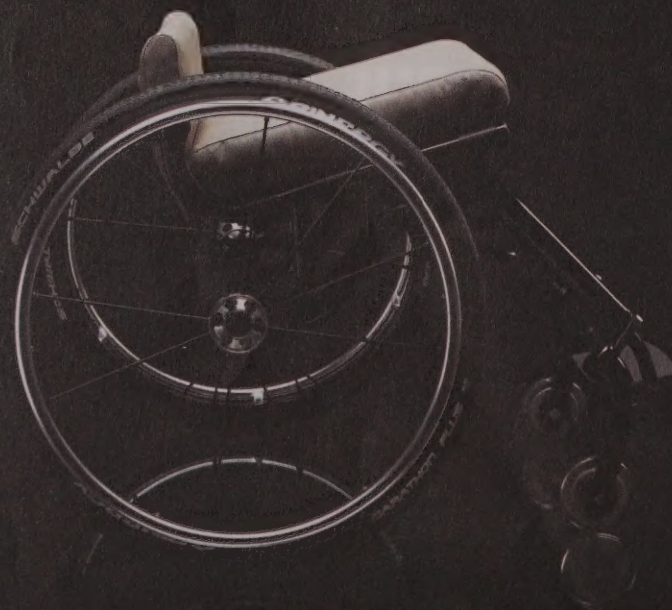
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Watkin brings **experience** to bear at DoH

The appointment of a new disabled co-national director for "learning disabilities" will help make a new Department of Health strategy a reality, says **Cathy Reay**

Scott Watkin, newly appointed as the new co-national director for learning disabilities at the Department of Health (DoH), has said that his appointment will help to ensure a focused delivery of equal rights for disabled people.

In an interview with *Disability Now*, Mr Watkin, who has learning disabilities, said that he now has a "huge responsibility on his shoulders" of making the strategy, Valuing People Now, which was passed earlier this year, a reality.

"I want to ensure disabled people have the same rights as everyone else. It's ridiculous that, in the 21st century, they don't yet have this.

Knowing there was more work to be done, the release of Valuing People Now in January served as a progress update on the campaign and lockdown plan of action for the next three years.

"The challenge for me, and for my team, is to make sure that people with learning disabilities



are heard and that all minorities are given equal rights and opportunities.

“In this day and age there should be an adequate platform for people with learning disabilities to speak and get noticed”

In this day and age there should be an adequate platform for people with learning disabilities to

speak and get noticed,” said Mr Watkin.

The role of co-national director of learning disabilities was introduced in 2006 as the first senior government post specifically created for someone with a learning disability. Mr Watkin said that he believes his personal experiences, particularly with the use of government services, will provide great insight into achieving realistic goals for the learning

disabled in the UK.

“I think that my skills and knowledge, drawn from not just my own experiences but also my previous work, plus a dedicated team behind me, will greatly aid my ability to provide the goals set out in the strategy plan,” he said.

The goals outlined in Valuing People Now include personalising services to be more suited to individuals (rather than setting a group standard that doesn't meet some people's needs), better choice of housing and a more accessible and attentive healthcare system.

“Personalisation is a big subject and services must work this way so that people with learning disabilities have a choice of where to go and what to do in life,” said Mr Watkin.

He previously co-chaired the Isle of Wight's Learning Disability Partnership Board, where he assisted in restructuring the board in anticipation of the Valuing People Now strategy.

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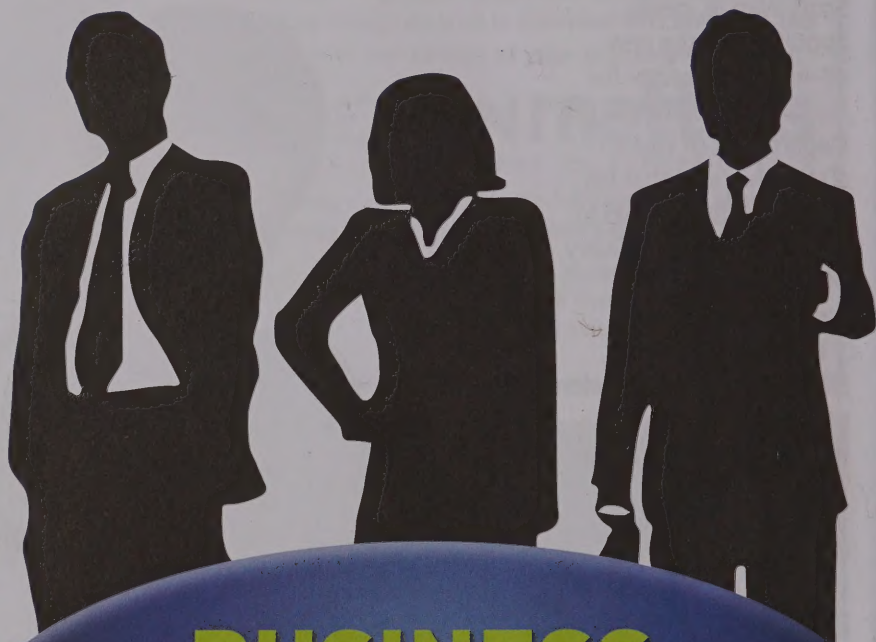
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'BNP spells **danger** for disabled people'



JOHN STILLWELL/PA WIRE/PRESS ASSOCIATION IMAGES

Sunil Peck

The BNP's success in European elections will be disastrous for disabled people, activists have warned.

BNP leader Nick Griffin was elected to represent the North West region while Andrew Brons won the seat for Yorkshire and Humber in the June 4 elections to the European Parliament.

Activist and campaigner Richard Reiser branded the BNP a fascist party and said that its electoral success was a result of large numbers of disillusioned Labour supporters failing to vote.

He said that disabled

people in areas represented by the BNP would be afraid because fascists wanted to kill disabled people.

"The fascist record on dealing with disabled people is to kill us. They're Holocaust deniers but I haven't noticed them denying that disabled people were killed en masse in Germany."

Julie Newman, Acting Chair of the UK's Disabled People's Council, said she could only think that a party denying the Holocaust would deny disabled people the right to exist too.

She said: "I think there's a eugenics agenda because they want to get rid of anybody who taints the

bloodline. I think that anybody who's different from the BNP's purist agenda is going to have a difficult time."

Alice Maynard, Chair of disability charity Scope, said that black and ethnic-minority disabled people already endured considerable discrimination which she doubted would improve with the election of BNP politicians.

"One feels that the BNP's approach to race is the negative bit, but I don't think that disability is ever far behind. There are serious issues around the genetic agenda."

All three campaigners said

that they hoped the success of the BNP would serve as a rallying call to disabled people to ally with anti-fascist and anti-racist organisations.

In May, the *Observer* newspaper reported that Jeffrey Marshall, senior organiser for the BNP's London European election campaign, had posted a message on an internet forum in which he commented on the death of David Cameron's disabled son Ivan.

According to the *Observer*, Mr Marshall said: "We live in a country today which is unhealthily dominated by an excess of sentimentality towards the weak and unproductive. No good will come of it."

The *Observer* article said that later, in response to comments made by others on the site, Marshall is alleged to have written: "There is not a great deal of point in keeping these people alive after all."

The *Observer* added that Mr Marshall said the comments were private and some had been paraphrased and taken out of context. The paper said that he had admitted making the former comment but said he could not recall making the latter one.

newsupdate

The Bill gets larger as disability claims rise



PICS ON STOCK / FOTOLIA.COM

Nigel Green

Seven times as many police officers are bringing disability discrimination cases against their forces as five years ago, according to figures released under the Freedom of Information Act.

Disability discrimination cases also account for more than a third of all tribunals brought against police forces and are estimated to have cost taxpayers more than £3.4 million over the last five years, of which £2 million was accounted for in the last year alone.

The rise is partly due to new laws that have made it easier for police officers to bring claims. In 2004, the Disability Discrimination Act 1995 was amended to cover the police.

But Scott Westbrook, President of the National Disabled Police Association,

also puts it down to modernisation and the increased employment of police officers who have suffered injuries.

"Forces want to reduce bureaucracy and get more police officers back out on the streets," he said. "I have no problem with that, but in some cases, it's like a witch-hunt to see who they can kick out of the job."

"They're not looking at the impact this is having on the workforce. That's why the number of employment tribunals has gone up."

The figures were released as part of a survey of all 51 forces in England, Scotland and Wales. This found that the number of tribunals brought against forces in the UK went up from 248 in 2003 to 405 last year.

But several forces failed to give year-by-year breakdowns and a quarter of all

forces refused to reveal figures on pay-outs and legal costs, apparently out of fear of breaching confidentiality agreements on individual settlements.

Of those forces that did supply figures, the number of cases brought on grounds of disability discrimination rose from 22 in 2003 to 148 in 2008. In the same period, race-related claims rose from 43 to 62 and sexual discrimination claims fell from 82 to 79.

Matthew Elliott, Chief Executive of the Taxpayers' Alliance, said: "It's shocking that so many police forces have been unwilling to obey the law on Freedom of Information."

"This is taxpayers' money and we have a right to see how it is being spent: police forces cannot simply decide to ignore the law."

Mr Elliott added: "Senior management of every police force must focus on working with officers who have disabilities, rather than simply trying to buy them off."

Asked if some officers used the Disability Discrimination Act as an excuse to seek an easier role or compensation, Sgt Westbrook said: "I don't think officers are abusing this Act. You'll always have the odd bad egg who'll try to use their difference to

get an advantage but they are few and far between."

Sgt Westbrook, who has osteoarthritis and works as a custody officer for the Met, declined to name the forces he considered the worst offenders but said: "Hampshire is a good force because it looks at what people can do rather than what they can't."

"They seem to value the experience and recognise its value. They don't want to waste their resources."

A spokeswoman for the Association of Chief Police Officers (ACPO) said: "There are several reasons why claims may be increasing and we are working with forces so that internal disputes can be rectified quickly, whilst ensuring that the welfare of the officer or member of staff is upheld."

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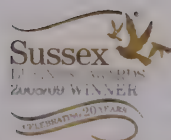
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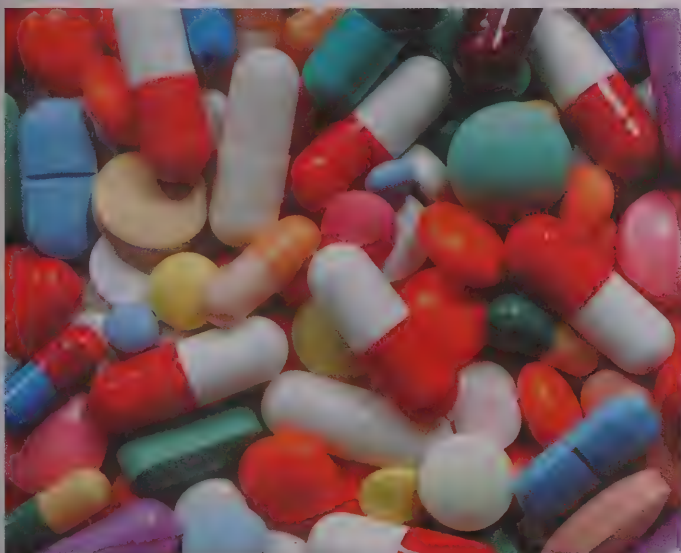


ruthpatrick

Prescription for action



In the wake of MPs' expenses, **Ruth Patrick** argues that it's time to put prescription charges very firmly on the disability agenda



ANDRZEJ TOKARSKI / FOTOLIA.COM

Reading the deluge of coverage on the MPs' expenses scandal and the outlandish claims for moats, church collections and plasma TVs got me thinking about the expenses that can arise from life as a disabled person.

As well as the costs of specialist equipment, extra heating and, on occasion, personal assistance, there is the frequent expense connected with necessary medication.

Unfortunately, however, while MPs have been able to submit extravagant claims

for questionable costs associated with their lives as politicians, disabled people usually have to pick up the tab themselves, particularly where prescription charges are concerned.

Thus, I find myself shelling out £7.20 every month for the medication that helps me to manage my mental health condition.

As a full-time worker, I can afford this expense but it still galls me that I'm expected to pay out for such an essential item that, if the NHS still worked to its founding goals, should be

provided free of cost.

What concerns me more is that some disability benefit claimants are also expected to pay for prescriptions, where their income places them just over the threshold for exemption from health care charges.

The impact of this is well-researched: a report by the mental health charity, Rethink, found that 38 per cent of those with long-term mental health issues often have to choose between paying household bills and paying for their prescriptions.

Furthermore, the Citizens Advice Bureau revealed that over 800,000 prescriptions are not collected each year, with cost being highlighted as a significant factor in dissuading some individuals from getting their pills.

I know that placing the spotlight squarely on medicine, and thus on impairment, is not always popular with the disabled community. Nonetheless, it is time to look beyond the social model and consider issues of impairment.

Prescription charges is one issue where discussions and campaigns from within the disabled community could well yield results.

Indeed, now is a vital time to campaign on prescriptions. At last year's Labour Party Conference, Gordon Brown promised to restore free prescriptions for all those with long-term health conditions and he has already removed prescription charges for those living with cancer.

A coalition of disability charities has launched the Prescription Promise Campaign, to demand that Gordon Brown's promise is translated into action so that one cost associated with disability can be removed.

Let's hope that in the midst of the expenses furore, Gordon Brown's promise to help with the expenses of disability is not forgotten.

To find out more, visit www.prescriptionpromise.org, which also contains a petition calling on the Government to act fast on prescriptions

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politics

Recession tops TUC agenda

Delegates at the TUC's recent disability conference were warned to beware of employers marking out disabled people for redundancy, reports **Sunil Peck**



NEWSQUEST (OXFORDSHIRE)

With unemployment edging towards three million, delegates at the TUC's recent annual disability conference in London expressed fears about the recession and its likely consequences on disabled people.

Mark Fysh (pictured), Chair of the TUC Disability Committee, said disabled employees would be first in the firing line as companies used lay-offs to cut costs, and warned the recession would make it even harder than usual for disabled people to find new jobs.

Fysh, a branch secretary for the union Unison, urged colleagues to make sure that sickness procedures were not used by employers to oust disabled people, and that any job losses were for genuine reasons and after

reasonable adjustments had been made by employers.

The TUC Deputy General Secretary Frances O'Grady warned delegates that unless unions challenged the unfair targeting of disabled employees, there was a risk of economic hardship.

She also foresaw a reversal of the slow, painful progress made over the past decade in increasing the employment rate among disabled people.

Ms O'Grady said: "Places like South Wales and the North East of England are still picking up the pieces of the Thatcher recessions of the early '80s and '90s, with a higher number of incapacity benefit claimants than anywhere else, and we simply cannot afford a repeat performance this time."

Delegates also raised concerns about the consequences of the Government's proposals for reforming the welfare system.

Echoing long-held fears among disabled activists, Ms O'Grady said that the Government had pandered to tabloid rhetoric about spongers and layoffs

instead of addressing the needs of disabled people.

She stressed the TUC's determination that disabled people would not be "victimised" by welfare reforms.

But Mark Fysh injected a note of optimism when he said that the widespread disillusionment with the political system could put disabled people in a position of power.

"There are enough disabled people in the country to make a political difference. If MPs want to be in parliament, they are going to have to prove their worth to the country."

Frances O'Grady pledged that the TUC would continue to fight for justice



NEWSQUEST (OXFORDSHIRE)

for employees of the Remploy factories.

Her comments came in the wake of the news that Remploy managers had shared bonuses worth more than £1.5 million at a time, according to unions, when factory closures have left thousands of disabled people out of work.

As Mark Fysh put it, "Given the fact that so many disabled people have lost their jobs, the award of the bonuses was appalling."



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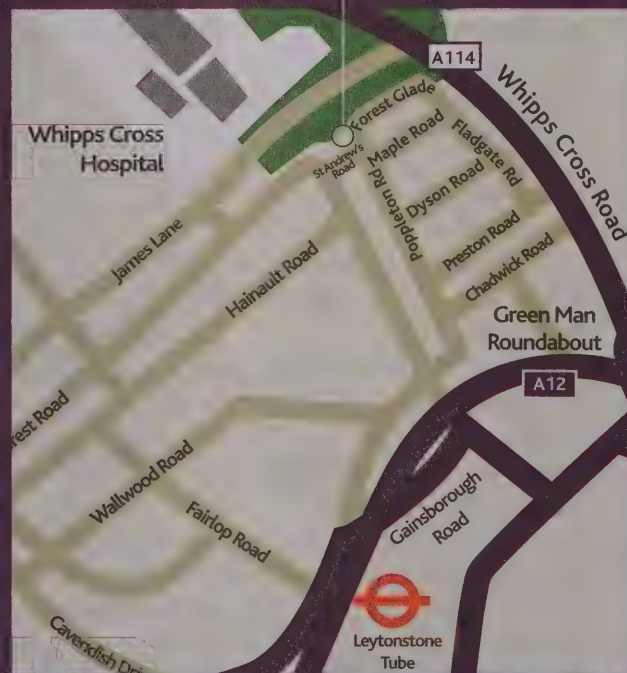
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mediawatch

Susan Boyle - The dream turns **nightmare**



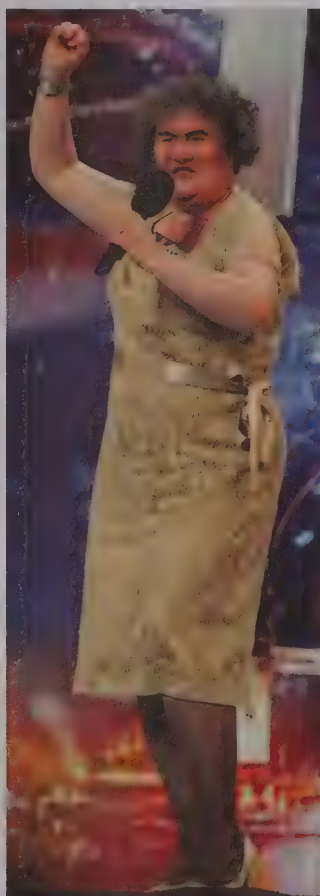
Is Susan Boyle now paying the price for presuming, as a middle-aged woman "with learning difficulties", to join in with a mainstream competition or, asks **Amie Slavin**, is she merely reacting in an entirely natural and understandable way to an extraordinary experience

As the media fall over themselves in the race to expert status regarding the possible effects of natal oxygen deprivation on the typical Britain's Got Talent hopeful, isn't it time we pause to ponder whose vulnerabilities "SuBo" has really touched on?

The media version of her supposed misdemeanours begins with a little physical theatre on stage, followed by a gracious and dignified withdrawal to the seclusion of her hotel room, where the pressure and anticlimax of the entire competition finally caught up with her and she cried – a lot.

If only she were "normal", how much better she would have coped. The music business is, after all, known for the impeccable behaviour of its star performers. It's not like any popular singer has ever gone so far as to damage hotel property, for instance, is it?

The pressure of weeks in the limelight, without her closest friend, Pebbles the cat, finally broke over her with such force that she



ITV / TALKBACKTHAMES

fainted. This resulted, somewhat dramatically, in her admission to the Priory Clinic, where she cried for Pebbles, flapped her arms at her handlers and, most distressingly, according to one *Sun* source, kept talking to herself, and then went quiet.

Heaven keep that source from ever popping round

The usual jealousy of celebrity was, on this occasion, exacerbated by Susan's unforgivable crimes of being nearly fifty, fat and frumpy, with a disability 🐘

mine, if he/she is so easily distressed!

Who has never felt isolated, anxious, homesick or overwhelmed by the loneliness of the crowded room? Who, other than rhino-skinned show-biz hacks, that is?

Susan wasn't even allowed to weep in her bedroom, unobserved. Is it any wonder that, with adrenalin congealing with disappointment, triumph and exhaustion, and surrounded by screeching, flapping meejah indispensables, the urge came upon her to physically prevent them from invading

her personal space?

The first truth about this is that, having exploited her allotted 15 minutes of fame, the day after the final the media were preparing for the feeding frenzy of the SuBo backlash.

The second, more sinister truth, in my view, is that the usual jealousy of celebrity was, on this occasion, exacerbated by Susan's unforgivable crimes of being nearly fifty, fat and frumpy, with a disability. If we, as a society, find other people's good fortune hard to stomach at the best of times, then how much worse for the viewing public to watch someone achieve stellar success without glamour and "with learning difficulties?"

A society that resists defining us by any other means than our disabilities, reserves the right to beat us over the head with them, if we show signs of forgetting our place.

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disabilityrights

Making the final call

The General Medical Council is urging disabled people to take part in its consultation on end-of-life care guidelines. **Ann Pridmore** asks some timely questions

The screenshot shows the GMC website with a navigation bar at the top: 'Regulating doctors', 'Ensuring good medical practice', 'The medical register', 'Registration for doctors', 'Concerns about doctors', 'Guidance on good practice', 'Education', and 'Public'. Below the navigation bar is a search bar with a 'Go' button. To the left of the main content area is a sidebar with links: 'Information for you', 'Patients and the public', 'All doctors', 'UK medical students', 'International Medical Graduates (IMGs)', 'Employers', 'The media', 'This month's hearings', 'Cases being heard this month', and 'Recent decisions'. The main content area features a large green banner for 'End of Life Care: tell us your views' with a 'Click here' button. To the right of the banner is a 'Welcome to the GMC' section and a 'Latest News' section with a list of recent announcements, including 'GMC announces launch date for doctors' licences' and 'GMC publishes answers to revalidation questions'.

As someone familiar both with consultations and with issues relating to end-of-life care, the two questions that most immediately spring to mind are: how many disabled people's organisations (DPOs) have been involved in this exercise, and how far have disabled people been involved in drawing up the guidelines?

In my experience, the views of people like me with

"life-limiting conditions" are often very different from those of doctors but doctors have more power. Their decisions can often affect our very existence, especially on impairments such as cerebral palsy and muscular dystrophy.

More questions arise about who makes decisions about starting or stopping life-prolonging treatments, such as artificial nutrition and mechanical ventilation that have been used

successfully across many impairments to help disabled people have a valued life on their own terms.

Who will actually make these decisions on behalf of disabled people and on what grounds? Decisions on whether or not to withhold treatment could be made, for example, on grounds of cost.

There is also the issue of "patients without capacity". My concern here is how this is defined. Disabled people with speech impairments have often been seen as lacking capacity. The guidance recommends "capacity advocates" to represent patients' interests but the Government has consistently refused to fund advocacy organisations and restricts advocates to people who have no family, friends or carers.

In any event, family members may not always be the best people to offer support. There may well, for instance, be underlying reasons why it may not be in their best interests to keep the relative alive.

I'm pleased to read that where patients feel pressured by family or carers to accept or refuse treatment, it's recommended they receive help. However, my concern is where this help will come from when there is no commitment to fund

advocacy services.

The guidelines are clear where a judgment needs to be made on a person's quality of life: "You must be careful not to rely on your personal views" or those of particular groups including disabled people.

As a disabled person, I'm fortunate enough to be able to articulate my views. This has not always resulted in the treatment I would have wished.

In some instances when people have a speech impairment, they've often found themselves not listened to.

My mother was advised that I'd never lead a full life because of my impairment. But here I am, about to reach 70, having a fuller life than some of my PAs

My own experience casts a cautionary light on the section on neonates, children and young people.

My mother was advised that I'd never lead a full life because of my impairment. But here I am, about to reach 70, having a fuller life than some of my PAs!

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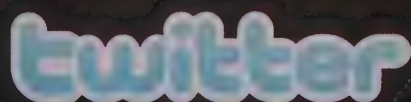
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From Russia with **rights**

Susanna Isajanyan, director of a new Armenian NGO, tells how her experience of life in Russia inspired her campaign for equal rights and better access for disabled people throughout the Caucasus

I'm the president/founder of Khariskh, a non-governmental organisation (NGO) for the disabled people of Syunik Marz, in the remote south-eastern region of Armenia. My hip bone was crushed

during a forceps birth. As a child I found it hard to walk; at 22, I lost all mobility and went to Russia for surgery. The recovery process was slow and I was warned I'd always walk with walking aids but I persevered and

now don't need them.

As a child I felt ashamed of my disability but my six years in Russia changed the way I thought of myself. In Russia I was treated as an equal, went to discos, lived a normal life and realised

that having a disability did not have to be debilitating.

Nothing much had changed in Armenia when I got back. People would still stare at me in the street and wonder how anyone with a disability dared go about in



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Armenia's high life: most housing lacks lifts, ramps and even handrails. Kharikh is trying to change that by holding conferences

public. But Russia had empowered me and I felt that all disabled people should enjoy the equality that I knew was possible, so I started an NGO called Kharikh to fight for equality for everyone disabled in Syunik Marz.

I'd also shared a hospital

room in Russia with people from all over the Soviet Union, including people from countries such as Azerbaijan with whom Armenia has always had a difficult relationship, and yet I found it was possible to form strong cross-border friendships. This also left a strong impression on me. So did my awareness of the fact that in the past, NGOs from across the Caucasus had met at conferences in Tbilisi, sharing experiences, talking about ideas, and building bonds.

It was this that led me to revive the trans-Caucasus conferences. And so on 3 December last year, Kharikh organised a trans-Caucasus conference for disabled people called "United in the Fight for a Brighter Future". Participants came from Georgia and Armenia as well as Azerbaijan and included people with disabilities, other NGOs and government representatives.

During the conference, representatives gave presentations on the issues that people with disabilities currently face in their respective countries and the work that NGOs and individuals are doing to solve those problems.

A recurring theme was lack of accessibility. All over the former Soviet bloc, buildings and public transportation were



Susanna Isajanyan: injured at birth, she's planning to invite the mayor of Sisian to try to get about his own city in a wheelchair

constructed without any thought of how disabled people might have to use them. Most Armenian apartment buildings were built during the years of the Soviet Union and range from three to ten floors high. Few had lifts; most don't even have ramps or handrails, and almost all have unnecessary steps that create additional barriers.

Kharikh will be hosting a second trans-Caucasus conference in December 2009, to be called "From Equal Rights to Equal Opportunities", and this will focus particularly on accessibility. In the city of Sisian where I work, we have already started to hold meetings with the mayor and city architect to discuss improvements in some of the larger stores in town. To emphasise the barrier that

stairs can be, we're planning to obtain wheelchairs and invite the public, as well as the mayor and other officials, to try and get around their own town in them.

I've faced many hardships in my struggle to become an NGO director in a society where people with disabilities are seen as second-class citizens, and where the role of women is relegated to the home. These challenges have only motivated me further to keep working towards making things better. Although there are still problems, and we're still a long way from equality, things have improved. Now when I walk down the street people don't stare at me; instead they ask me about my current projects.

Susanna Isajanyan with Mari Chiba

onetowatch



Sarina **out-sparkles** the competition

The votes are in for the Jewellery Channel's design contest and the winner is Sarina Morris. As well as having her glittering creations manufactured and sold, Sarina wins a contract as a freelance designer for the Jewellery Channel, but having more than one string to her beads, she's still ambitious to shine in the spheres of painting, interior design and fashion. Sarina puts her gloss on our ten questions and reveals why you can't judge a jewellery designer by her appearance.

What's the best thing about being disabled?

It can certainly enlighten you and bring you into a world that you didn't know existed. I've become more in tune with myself and appreciate life.

What makes you angry?

People who take one look at me and say: "But you look great!"

What's the funniest thing anyone's ever said to you about your impairment?

"I wish I had what you have: I could do with losing this weight!"

If you were Prime Minister what one thing would you do to improve things for disabled people?

For my condition especially, I would increase the amount of public toilets and their ease for accessibility, including cost.

What's the one thing that could be invented to make your life as a disabled person better?

Non-surgical, non-steroid, pill-free treatment for Ulcerative Colitis. Oh yes, and brand new bones.

What do you most like about designing jewellery?

The creative outlet it gives me, and the practicality of being able to design from the comfort of my own home.

And what do you not like about it?

Not being able to afford the very high-end pieces I'd love to own and add to my jewellery collection.

Who's your favourite disabled person ever?

Stephen Hawking. I admire his ability to not let his condition get in the way or hold back his passion for his research.

Do you have any special or hidden talent?

I did once make it through to the second auditions for a girl group, so singing and dancing.

How would you sum yourself up in ten words or less?

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Live your Life

Running man Pistorius is back!

Following a brush with near death in a boating accident, Oscar Pistorius talks to **Paul Carter** about getting his life and career back on track

On the 16th September last year, under the glare of the world's attention, Oscar Pistorius crossed the finishing line in Beijing's Bird's Nest Stadium to claim his third gold of the 2008 Paralympic Games, his fifth Paralympic medal in total.

Having truly arrived on the world stage as one of the first superstars of disability sport to cross over into the mainstream public consciousness, life, it seemed, could not get much better for the athlete nicknamed "the fastest man on no legs".

However, just five months later, the Blade Runner's outlook suddenly appeared very different.

A serious speedboat accident on the Vaal River in his native South Africa

left Oscar in a hospital bed, bloodied, bruised and with his jaw wired shut.

He was in a coma for three days.

"I hit a solid concrete pier that was 7cm under the water," he explains. "We were going into the sunset and it was dusk so we couldn't see it."

"We hit this thing at about 35km an hour, which is quite quick, and I hit my head against the steering wheel."

The extent of Oscar's injuries was shocking. The 22-year-old fractured his eye socket, jaw, nose, forehead, elbow and several ribs.

We meet three days before he is due to run in his first competitive races since his accident, the 100m and 400m at the Paralympic World Cup, itself a remarkable feat in such a small amount of time. There is little evidence of a man

recovering from serious injuries, save for a couple of small scars on the back of his head that belie their seriousness.

"It was a serious injury but I'm feeling a lot better now, getting back into shape and feeling stronger."

Oscar is a man used to overcoming challenges. Last year saw the culmination of a long running battle with the International Association of Athletics Federations (IAAF) over his eligibility to compete in international competitions with non-disabled athletes.

The IAAF initially banned him from competing after running tests on his prosthetic blades, deeming that these awarded him "clear mechanical advantages."

Oscar refused to accept the ruling, and took his case to the Court of

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“If I see a kid in a supermarket staring at my prosthetic legs I’ll go up to the kid and I’ll say ‘hi, my name’s Oscar and I’ve got artificial legs. The reason I have this is because of not having tibia or fibula in my legs and I live a very normal life’”

Arbitration for Sport, which overturned the IAAF’s ruling.

“I don’t think the way the IAAF went about it was fair,” he says.

“They said that if they let amputees run, it’d be like letting people use jet-packs. It was small comments

like that that weren’t fair but I can also understand where they’re coming from.

“When they did the tests I thought it was really important that we go and redo tests and prove that the prosthetic leg that I use, and that most of the top Paralympic athletes use, isn’t a performance enhancing piece of equipment. That was obviously something we had to do.”

The decision to allow him to compete with non-disabled people divided opinion among the disabled community.

While some were happy to see a disabled athlete competing on an even keel, many others were concerned that it would devalue Paralympic sport, or even reinforce the “two-tier” impression that disability sport has

worked so hard to shift. Oscar is fiercely critical of this point of view.

“I think what you want at the end of the day is inclusion,” he says. “You don’t want to be distinguished. I think the Paralympics has a very important place in sports and I think it’s always important that it is there because it caters for sports that aren’t in the able-bodied mainstream, but I think if you can bridge the gap, then fine.

“Probably along the way I’ve encountered one or two athletes – just literally one or two – who haven’t been happy running against me, and it’s usually after I’ve beaten them!

“I think that at the level we compete at, it’s a good thing that we had to go through the IAAF saga because there would always have been an athlete or ➔

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two that maybe had a question or queries, and having gone through that now they can say 'if I lost against this guy it's not because of his legs, it's because I need to train harder'. If I lose a race I don't look at other people and think 'he's doing better because he uses this or he uses that'. I go 'I haven't trained hard enough; I haven't prepared, I wasn't mentally strong enough, my reaction speed wasn't quick enough.' You look at yourself."

As it turned out, Oscar failed to reach the Olympic qualifying time to run in Beijing with South Africa's 400m squad.

Did that tinge his experience of the Paralympics with disappointment?

"I think it was disappointing at the time, but when I look back at the year I had such an amazing time at the Paralympics that it didn't really matter.

"Although I'd like to compete in the Olympics one day, the Paralympics are

just as important to me. I just thought, 'well, I might not be able to be at the Olympics this time around but the Paralympics was awesome'."

However, he admits that the pressure of expectation did take its toll.

“Probably along the way I've encountered one or two athletes – just literally one or two – who haven't been happy running against me, and it's usually after I've beaten them!”

"I think for me it was very tiring in a sense you know? When I was in Athens [in 2004] I didn't really feel much pressure because I was the underdog; I'd only been running for eight months and it was all very new.

"But I definitely felt a lot more pressure being in Beijing, it was a

lot more difficult.

"Obviously the goals we had were a lot more hectic, but then I got sick after the 100m and then really sick after the 200m so I was really not feeling up for anything, but then the 400m race was awesome.

"It was so great to finish off; it was the last race in the Bird's Nest. It was the biggest crowd I've ever seen, 94,000 people. I was super-psyched, it was just mad, but when I crossed that last line I was just thinking 'you know, I'm really glad this competition this year is over, it's been extremely long'. It was awesome but it was pretty tiring."

After the media coverage of his battles with the IAAF, an ill-fated televised race against non-disabled athletes in Sheffield, and his successes in Beijing at the Paralympics, few could argue that Oscar is now one of the most recognisable disabled people in the world, with a popularity that transcends beyond sport.

When I ask him if he is comfortable with being a role model, there is a noticeable awkward shift in his seat.

"I always laugh when people ask me that! I don't know. Obviously I know there's responsibility that comes with being in the limelight of sports and stuff. I don't think it's really hit me that I'm in the position that I'm in.

"I'm just very grateful to be an athlete and be good at what I do, one of the worst things would be to have to look back at a career and say you haven't achieved your utmost potential.

"I think there are so many role models that are doing a lot for Paralympic sport, and if I can be a part of that and be a piece of the puzzle then I'm very happy to do that."

Following the Paralympic World Cup, Oscar reveals he has a busy schedule, with races lined up in Italy, Spain, Scotland, Norway, Greece and



France – all but one of which are non-disabled meets.

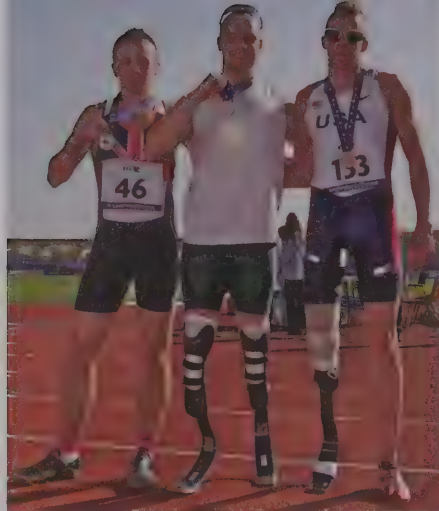
"Then I think I'm going to take a break and go home for a couple of weeks," he smiles.

Home is the South African capital, Johannesburg, where he was born and raised, the middle child, with a younger sister (Aimee) and an older brother (Carl).

He says that awareness of disability in his homeland is "getting there" and has improved in recent years, but concedes that there is still room for improvement.

When the subject turns to awareness and education of children, Oscar's eyes light up, and he speaks with conviction and passion.

"Someone didn't agree with me the other day when I said, 'if I see a kid in a supermarket staring at my prosthetic



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legs I'll go up to the kid and I'll say 'hi, my name's Oscar and I've got artificial legs. The reason I have this is because of not having tibia or fibula in my legs and I live a very normal life.'

"I think if you make kids aware they're not going to stare and they're going to be like, 'oh there's a guy with prosthetic legs, there's a guy with normal legs, there's a guy in a wheelchair.'

"I've only ever met one or two people out of the literally thousands of disabled people I've met who aren't

prepared to talk about their disability. I think that's where it needs to be where people are aware of disability."

For a man who has achieved so much considering he only began running eight months before his first Paralympic appearance in 2004, what are the future ambitions?

"I'm looking forward to London 2012 now and hopefully doing the 100m, 200m and 400m again there, and just to stay on the top of my game. It's not pressure from anyone, it's just pressure from yourself, you know? There are always new guys coming up and as quickly as I came into the sport the next guy could, so I'm just enjoying what I do, training and using my ability to the best and not wasting it."

Somehow, that seems unlikely to happen. ■

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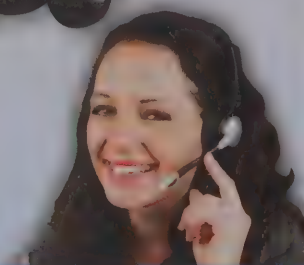


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Open to abuse

The publication of a report on abuse of people with dementia has raised questions about levels of abuse affecting disabled people, across the impairment spectrum, living in the social care system.

Cathy Reay investigates

Margaret Rylett, mother of Amy, a 23-year-old girl with cerebral palsy (CP), epilepsy and learning difficulties, says her daughter is being abused but no-one believes her.

"I'll complain to anyone who might listen – her carers, social services, managers at the care home; they tried to tell me that she harms herself... but it's physically impossible for that to happen. We don't know where to go for support," she told *Disability Now*.

The Government has pledged to stop the abuse of vulnerable adults, whether in a home or care environment, but a University College London (UCL) study conducted in January 2009 found that over half of adults with dementia have

been mistreated by a family carer, through neglect, theft, physical or emotional abuse.

To *Disability Now's* knowledge, this is the only significant research in recent years into carer abuse, an issue that has been significantly overlooked by the Government and the media.

Furthermore, when we contacted disabled people to talk about abusive care, we were met with reluctance from disabled people too afraid to speak out.

"I'm too scared that my abuser will read this," revealed one woman. "I'm still being abused and I'm worried that talking to you will make it worse for me."

Willing to speak or not, everyone we contacted wanted this story to be forced into the public eye so the Government

might consider providing better measures to ensure the safety of disabled people who rely on care giving.

Neil Hunt, chief executive of the Alzheimer's Society, said: "It is essential that those working in the fields of health and social care are given appropriate training, backed up with ongoing assessment and better regulation, to ensure standards of care in all settings are driven up. There is no excuse for abuse and we should not rest until it has been eradicated."

Mrs Rylett agreed. She first suspected something was wrong with Amy's care in July 2007 when she was told her daughter had fallen out of a chair. "We had the same chair at home and had had it for years, it was very secure and

she'd never fallen out of it before.

A couple of months later Amy was driven home on a bus and she was crying; she was obviously in pain. The seat she was on had been tampered with and she had been forced into a really uncomfortable position. Nobody had helped her."

Since then, Amy has also come home with mysteriously swollen ears and a stabbed thumb. Mrs Rylett is desperate to move her daughter to another day care centre but as they live in Anglesey, there isn't much choice. "There are only two others near us and they said they are full. I don't know what to do."

Gary Martin, former head of policy at Action on Elder Abuse, told *Disability Now* that Amy's case is unusual. "Physically abusive carers in the UK are not common, but neglect and abuse of trust often features in a carer-patient relationship," he said. "People try to put the Hollywood treatment on things like this by insinuating that abuse is purely physical, but often it's the less noticeable things that those in power can do to vulnerable people that can be more damaging."

This is evident in the case of one woman, who has learning difficulties and wanted to remain anonymous, who told us how, over five years, a

“She told me that she was going to lose her home because she couldn't pay the mortgage. I was actually taking her to the cash point and getting money out for her without realising that it mounts up. I'd give her about £300 each time, sometimes more”

“She took off her top in the shower and propositioned me and tried to kiss me. I told her it wasn't appropriate; she was helping me to wash in the shower, it felt like an abuse of power. She could have told me before, when I was clothed, but maybe in that moment of confidence she thought, well, 'he's naked and vulnerable'. And I was”

carer coerced her into giving her over £7,500 in cash. "She told me that she was going to lose her home because she couldn't pay the mortgage," the woman explained.

"I had just come into quite a bit of money as my parents died. I was actually taking her to the cash point and getting money out for her without realising that it mounts up. I'd give her about £300 each time, sometimes more."

The woman said that, although she knew what the carer was doing was wrong, the longer it continued the guiltier she felt. "She was wrong for

asking me and I knew what she was doing was wrong but I felt like I was encouraging her by giving her the money. I didn't want to have to ask for help because I felt like it was admitting I couldn't be independent."

Eventually she told a neighbour who then informed social services and the police were called. With the help of Respond, a charity supporting people with learning disabilities affected by abuse, the anonymous woman was reimbursed in full.

Noelle Blackman, director at Respond, said that without Respond's help, the woman wouldn't have seen her money again. "This woman needed that support we offer to support her through claiming her money back."

"We are hoping to find the funding to reopen our support helpline facility at some point in the future as, until then, many families will find it difficult to find the kind of ongoing support that we offered."

The woman didn't press charges on her carer, a decision she now regrets as, when she made it, she wasn't given any guidance or support on speaking to the police.

Sylvia and Michael Brookstein, the former of whom has learning



JAMIE TROUNCE



JAMIE TROUNCE

difficulties, also turned to Respond when they had a rude and neglective support worker. "One day, on the way home from shopping, she got stroppy and said she was going home. It was only 11am, two hours before her shift finished, and we were stranded with the shopping," said Mrs Brookstein.

Mrs Brookstein added: "We complained to the head office and she got the sack. Afterwards, she would come round and just stand outside, the second time she rang the doorbell and asked to come inside but I said "no way". So I told the manager as soon as I could – I was worried about what she might do if she could come inside the house."

Ms Blackman said that it was lucky the Brooksteins knew who to turn to, as often people don't know. "It can be very difficult for people who are being abused by the people they are dependent on to know what they can do to stop the abuse," she said.

"Social services need to ensure that they give clear advice to people about who they can talk to if they are unhappy with the support they are

“I'll complain to anyone who might listen - her carers, social services, managers at the care home; they tried to tell me that she harms herself... but it's physically impossible for that to happen. We don't know where to go for support”

receiving. They also should consider advocacy schemes whereby isolated people have someone independent who is keeping an eye on the kind of care they are getting."

An anonymous disabled man with CP said that, during university, his boundaries were frequently tested by his constantly changing roster of personal assistants. "There was one guy, who was only 20, who was very awkward around me whenever I was naked. He would stand there and look up at the ceiling when he was supposed to be helping me wash.

He left the job two months in and a year later he called me to apologise for his behaviour. We maintained contact and eventually he told me he'd been in love with me all along and that he wanted to be with me and if he couldn't be with me, he'd kill himself."

In the same year, the same man was approached by one of his female assistants. "She took off her top in the shower and propositioned me and tried to kiss me. I told her it wasn't appropriate; she was helping me to wash in the shower, it felt like an abuse of power. She could have told me before, when I was clothed, but maybe in that moment of confidence she thought, well, 'he's naked and vulnerable'. And I was."

Looking back on the situation now, the man feels his care problems could have attributed to why he felt so stressed that year.

"My attitude in dealing with it was just to move on and get on with life, which is good because you don't want anything making you unhappy, but it does affect you underneath the surface

even if you don't realise it," he said.

"The important thing is that you feel you can tell people. I'm a confident person so I had no problem telling my friends and family about these carers and what they had done, which helped me to feel more confident around them afterwards, because I knew that if anything bad happened people would be aware of the signs."

However, not everyone has had such an empowering experience, which is why Claudia Cooper, a senior lecturer in older people's mental health at UCL and lead author of the study into caring for family members with dementia, hopes that her research will help to guide Government into working on new plans to combat carer abuse.

"The main aim of our research programme is to develop ways to



JAMIE TROUNCE

Neglect is just one of the ways carers can abuse disabled people

reduce or prevent abusive behaviour. We needed to know the scale of the problem to work out how to tackle it, and we are now going on to look at ways of reducing and preventing abuse," she said.

Ms Cooper's study was based on carers that came forward admitting that they had abused a family member in their care. But because many carers were too afraid to talk about what they may

have done, the figure could actually be far more startling. "Some abuse will inevitably be hidden, and this may be the most serious abuse," she said.

Disability Now believes that it is vital that this issue is addressed to protect disabled people from potential vulnerability in the environment they are supposed to feel most safe. Strategies should be put into place that look at providing relief and support to carers, plus a better vetting system through employment stages and regular progress checks while they are at work. These are just some of the ideas experts asked the Government to review but the Department of Health has said that it is still considering what to do. Meanwhile, behind closed doors, the abuse continues. ■

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yourviews



Cold weather, hot topic

I read your article on cold weather payments (*Disability Now*, Ruth Patrick, June 2009) and totally agree with your campaign.

I'm disabled; so is my husband. We both get DLA, our income is limited

and we struggle with high fuel prices.

We have no faith in MPs: they don't do anything for people like us. They only want to use our money to live a good life while we all suffer in poverty. I'll never

vote for them again.

I'd like all disabled people to get fuel payments so we can keep warm without the worry of big bills. I hope this helps with your campaign.
Mrs E Stebbings, Hull

how our representative represents us at EDF conferences. I envisaged that disabled people would eventually be able to participate in the selection of their representative to the EDF who would thereby be answerable to his or her electorate, a form of participatory democracy that I hoped would be copied elsewhere in the EU.

Mr Reiser purported to be very enthusiastic about this suggestion but, thus far, nothing else has happened.

I would be interested in launching a pan-European, online petition demanding democratic rights for disabled people.

Tony Kelsall, by email

Extending European democracy

In response to Andy Rickell's piece (*Disability Now*, June 2009), disabled people do not derive the same degree of benefit from EU membership as less disadvantaged groups.

For example, the European Disability Forum (EDF) proposed the introduction of a disability-specific directive that was submitted during the European Year of People with Disabilities (1993) as "a proposal for a directive based on Article 13 of the treaty with a view to combating discrimination

on the grounds of disability".

The main focus of Article 13 is to fight discrimination. It's not concerned with the introduction of specific advantages because affirmative action measures are beyond the legislative scope of Article 13.

Article 141 on gender, by contrast, includes affirmative action measures to compensate for the effects of past discrimination and address the under-representation of a protected class in today's workplace.

A similar comparison can be made in relation to other disadvantaged groups, for example in relation to race.

The above can be partly attributed to the poor representation of disabled people at the European Disability Forum (EDF).

The unpaid UK representative to the EDF is London-based Richard Reiser (Director of Disability in Education), a paid government employee!

In August 2006, I met him and offered to assist him in enabling disabled people in the UK to benefit from our membership of the EU.

I suggested the creation of an EU disability website, to help disabled people give more attention to EU issues and exert an influence on

Small change in benefit payment

I received an enquiry from one of our members regarding the letter in this month's *Disability Now* magazine: "Paying the price of change?", about possible loss of benefit (*Disability Now*, Letters, June 2009).

The main problem, I think, is that some people might find themselves in the position of not receiving benefits for up to three weeks during the transition stage, but they can apply for an interest-free loan to help during that period.

Readers might find the following Jobcentre Plus

links useful:

• Summary of the Changes to pay periods and pay week-ending days

http://www.jobcentreplus.gov.uk/JCP/stellent/groups/jcp/documents/website/content/dev_016121.pdf

• DWP advice to providers:

http://www.dwp.gov.uk/supplyingdwp/what_we_buy/notice_to_providers_paydays170209.asp

Mary Dyet
Information Services
Assistant, Sense

A sharp reality check

In your last issue (*Disability Now*, Editorial, June 2009) you referred to Chris Woodhead, who had remarked in an interview in the *Sunday Times* that he'd rather kill himself than die in agony, and finds it humiliating that his wife has to do everything around the house.

Of course I agree with you that such remarks will do nothing to dispel the negative social image of disabled people. But we need to reflect on the way society makes those of us feel who become disabled late in life.

Where's social inclusion? I'd consider myself socially liberated and politically aware: I was National Secretary of the World Development Movement when a car wreck head-injured me. Although I'd addressed global poverty

and the racial divide, I regret that politically I was totally unaware of disability.

After I came out of hospital, it took three years before I'd be seen walking with a stick. That's what the label does: "If I haven't got a stick, I can't be called disabled. The fact that I regularly fall flat on my face is irrelevant. They'll just think I tripped."

After years of psychotherapy I finally accepted that I was a disabled human being – and proud. I started Enabling Theatre, using Augusto Boal's Theatre of the Oppressed to address issues that disable. We're currently setting up Enabling Radio to reach a far wider audience.

Chris Woodhead should use his experience as former Chief Inspector of Schools to explore and promote ways of creating a fully inclusive education system so that kids grow up knowing that we're normal too. Installing wheelchair lifts isn't enough. Until schools address the social concept of disability, we'll continue to be a divided society.

And Chris might feel he still has something valuable to contribute to our society, in moving beyond the "you're a useless human being" disability trap.

Susan Quick,
Artistic Director,
Enabling Radio

Disabled's fashion-able

Regarding Peter White's remarks on supermarkets' making a virtue of stocking "living aids" (*Disability Now*, *Pete's Place*, June 2009), I've come to a similar conclusion but from a different direction.

As accessibility adviser to the tourism industry in Wales and Scotland, I've noticed a few initiatives crossing the boundaries of ability. Some years ago "wet rooms" were

installed mostly for wheelchair users: now everybody recognises their benefits and accommodation providers are installing them for walkers, cyclists, fisher-

men, families – all of us.

The same with Walkman tape-cassette audio guides to walking locations and places of interest: at first they were the domain of visually-impaired people. Now,

everybody

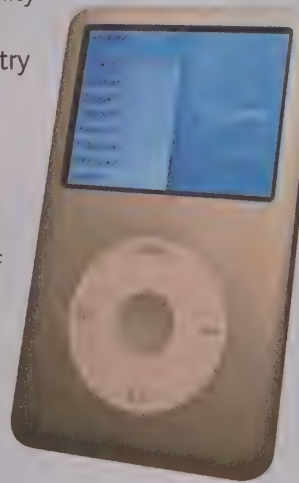
wants one as an iPod or MP3 download.

As someone said to me over 12 years ago, "we disabled people are at the vanguard of developments for all of us."

Yes, Peter:

attitudes are changing. I'd even go further and say that accessibility's becoming fashionable!

Colin Antwis, by email



Other side of DV coin

I noticed an advert in the May issue of *Disability Now* sponsored by Women's Aid about domestic violence, and highlighting the horrific fact that it occurs to

disabled women.

Sadly, domestic violence is meted out on men too and, it follows, disabled men. Who's going to stand up for them?

Spencer Arnott,
Homer Green, Bucks

→ Have your say

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- email us editor@disabilitynow.org.uk

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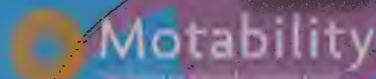
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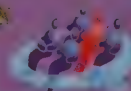


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Voting for a **bigger voice**

Having recently failed to win a council seat in local elections in Cirencester, Gloucestershire, **Andy Rickell** is prompted to reflect again at the lack of disabled people in politics

I have previously been a county councillor and a district councillor in Cheltenham, so this was my fourth time in a public election.

Generally though, disabled people, and certainly those who are impaired from early in life or who are obviously impaired or who face significant barriers, are seriously under-represented

It has reminded me about the commitment of all main political parties to see more disabled people become elected representatives at all levels of government, and the public sector duty to encourage the participation of disabled people in public life.

Currently disabled people are, as you might expect given our absence from powerful roles generally, under-represented as MPs and councillors too.

Actually amongst local councillors we do better than one might expect, but this is because the usual profile of a councillor is someone who is older and often retired, who therefore is more likely to be impaired due to age. Generally though, disabled people, and certainly those who are impaired from early in life or who are obviously impaired or who face significant barriers, are seriously under-represented. This is particularly an issue bearing in mind that of all sections of society, disabled and older people depend more for our quality of life on the state than anyone else.

What needs to change to get more disabled people elected? Perhaps the biggest barrier is public perception, and the reaction of political parties to it. The widespread ignorant presumption of the incompetence of disabled people means we are seen as less capable of holding responsible office – witness the discussion there

was about the impairments of Gordon Brown and David Blunkett. This then works through the system.

For example, by far the majority of MPs and councillors get elected as members of a main political party. So the disabled candidate who is serious about getting elected needs to be selected by such a party. We already know of the under-representation of

Currently disabled people are, as you might expect given our absence from powerful roles generally, under-represented as MPs and councillors

women and people from BME communities as parliamentary candidates to see that those responsible for selection decisions fall back on safety, and assume

that anyone other than a white male non-disabled candidate may be an electoral risk.

Having managed to convince a selection panel and be adopted as a candidate, the disabled person must then convince the electorate. At both steps this often involves the disabled person proving they are someone extraordinary, which is unfair. What is needed is a positive commitment by political parties to assertively select good disabled candidates and then assertively recommend them to the electorate, maximising their strengths and deliberately addressing any areas where the electorate may worry. Undoubtedly the best proof of the effectiveness of all disabled elected representatives is when they are given the chance and do a good job.

→ Have your say

- write to us Disability Now, 6 Market Road, London N7 9PW
- email us editor@disabilitynow.org.uk
- phone us 020 7619 7323

asktheexperts

you ask, they answer

QUESTIONS AND ANSWERS

Q My mother is taking me to Boston, Washington and New York in September this year. I wonder if it's possible to hire an electric scooter in each city we visit, and whether I need to apply for a disability parking permit for the three weeks we're there.

Michelle Turrell, by email



Andy Wright says: There's no national system of parking

concessions for disabled people in the USA. Most states operate their own individual schemes. The type of badges used and the concessions provided are not standardised and vary considerably. It's entirely at the discretion of the authorities in each state whether disabled motorists' badges issued in other countries are recognised, or indeed whether a local

temporary badge can be issued. While most states do their best to accommodate disabled visitors from the UK, they're not obliged to do so. In the meantime, you may find it useful to contact one of the following organisations:

- The American Automobile Association, 1000 AAA Drive MS No. 20, Heathrow, Florida FL 32746-5043, USA
Tel: 001 407 444 8036
 - Visit USA Association, 0891 600 530
 - US Travel & Tourism Administration, Tel: 09069 101 020
 - US Embassy, Tel: 020 7499 9000.
- To hire an electric scooter in North America, your best bet is probably to contact the following:
- Scooter and Wheelchair Rentals, which serves over 500 locations across North America, Tel: 001 888 441 7575.

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Q The directgov website states the conditions for free road tax for disabled drivers. I'm 79 and receive Attendance Allowance because of my disability but don't receive Disability Living Allowance or the War Pensioner's Mobility

Supplement (WPMS), but I have a mobility scooter. When I contacted the relevant government department about this, the person I spoke to seemed unsure about the conditions but thought that in order to qualify, ownership of a scooter had to be linked to

THE EXPERTS

We have experts who can answer questions in many areas that matter to us.

Sexual & Personal issues:

Simon Parritt, a counselling psychologist who has studied psychosexual therapy, was the only disabled director of the

Association to Aid the Sexual and Personal Relationships of People with a Disability (SPOD).

Legal Matters:

Douglas Joy, senior solicitor at the Disability Law Service, and his colleagues give advice on

disability and the law.

Benefits and Debt issues:

The **Citizens Advice Bureau** puts its expertise at our disposal to help you.

Technology and Internet:

Léonie Watson from digital consultancy Nomensa is here to get you

connected and keep you up and running.

Specialist or Adaptive Equipment:

John Mandrak, for nearly 25 years a disability journalist and consultant, gives advice on the Disabled Living Foundation's helpline.

one of the other conditions. I can only walk a very short distance and when I'm out it has to be by car or scooter.

Ian H Kemp, by email



Helen Smith

says: I'm afraid that even though you're

a disabled person who uses a mobility scooter you don't qualify for road tax exemption. This concession is only available to people who receive the Higher Rate Mobility Component of Disability Living Allowance (HRMCDLA) or WPMS. I'm afraid that Attendance Allowance (AA) is not one of the qualifying criteria as it doesn't contain a mobility component. You can only claim HRMCDLA if you became disabled before you were 65 and many older people are in the same position as you. Mobilise believes this is age discrimination and is totally unacceptable. I don't know

why the person in the government department was unable to help you but if you need more information, visit www.direct.gov.uk.

Can you give me any information about my local council's statutory duties in regard to housing adaptations for disabled people? For the past five years I've been trying to obtain a Disabled Facilities Grant (DFG) to build an extra bedroom for a live-in carer. For 15 years I've lived in a housing association bungalow that to begin with was adapted appropriately for my progressive neurological condition, but with only one bedroom it's not suitable now I need a live-in carer. The council won't give me the funding I've asked for because DFGs, it says, are only for a room I'd use myself. I've now put my name on the waiting list for a two-bedroom council property.

The council has recognised my need for an additional bedroom and has offered me an ideally-located two-bedroom bungalow but won't extend the bathroom, although this could quite easily be done, because it will not pay for adaptations to its own buildings, only to those owned privately or by housing associations. Can I challenge this?
Name and address supplied, by email



Kate Shehan responds:

Councils may turn down

funding for carers' rooms, as they're not part of the DFG provision but they can consider it under a discretionary grant. With regard to the new property that you're being offered, if

you've accepted it and it's going to become your main residence, the council has a duty to adapt the bathroom to meet your individual needs under the DFG legislation. The DFG is tenure blind, which means that any tenant, owner-occupier or tenant privately renting can apply for a grant as long as the welfare department (usually Social Services) states that the work is necessary and appropriate. Most council housing departments tend to fund adaptations via their own internal budgets but if they don't want to do this then you have a right to apply for a DFG to alter your bathroom to meet your needs. I'd recommend you contact your local Social Services Occupational Therapy service and request an assessment.

→ If you have a question for our panel

- phone us 020 7619 7323
- write to us Disability Now, 6 Market Road, London N7 9PW
- email us editor@disabilitynow.org.uk

Travel: Andy Wright is managing director of Accessible Travel, a specialist tour operator providing holidays for people with mobility impairments, and has huge experience in the travel trade.

Money management: David Clarke has spent 14 years in banking and has worked for three leading financial service providers. He is now a senior partner with Clydesdale Bank and his wealth of experience is all yours.

Access & the Environment: Agnes Fletcher is a disability trainer and consultant who can find solutions to access problems.
Property: Kate Sheehan is an independent occupational therapist with 20 years' experience and a

passionate interest in housing solutions for disabled people.

Motoring & Transport:

Helen Smith of Mobilise steps outside her *Disability Now* column to answer your questions on car matters.

pete's place

Purnell's lack of fitness



When James Purnell joined the list of high-profile rats deserting Gordon's foundering ship, it struck **Peter White** that he was also leaving the Department of Work and Pensions, and the noble task of welfare reform

Whoever holds the welfare reform brief, the rhetoric remains pretty much the same, particularly in terms of "getting disabled people off benefits, and into work".

It goes something like this: "The numbers of people on incapacity benefit are all the fault of those wicked Tories, who shoved people on to what was then called

invalidity benefit in the '80s, but we know that those nice disabled people really want to work, if they're only given the chance.

"Although, as it happens, there are a lot of scroungers out there, and quite a lot of them seem to be disabled, or saying they are. Oh, and by the way, if you won't look for work, we'll take your benefits away".

Let's try to shed a little

light on these assumptions, shall we? The numbers of people on incapacity benefit did go up sharply in the '90s, largely due to the compassion and common sense of many GPs in places like the North-East and South Wales, where many people were coming to the end of back-breaking lives in mining and other forms of heavy industry, with only the dole to look forward to. Most of them have by

now reached and passed retirement age.

So why haven't the numbers on incapacity benefit (still up around 2.6 million, where they've been for well over a decade) gone down? Well, for various reasons, but perhaps most noticeably, because of the increasingly stressful nature of the working environment.

Somewhere near 40 per cent of those now claiming work-related benefits have conditions like stress, depression, and other mental illness.

It's almost certainly true that if asked in a survey, "do you want to work?", most disabled people would say yes. The little phrase which is missing from this calculation is "at any price".

Most of the Work and Pensions ministers have been pleasant and humane, but as they looked at the situation, they realised the complete mismatch between rhetoric and reality; and then they left.

The only difference for James Purnell, was the added little problem of unemployment figures rising above three million. Could he simply just have thought: "This is a no-brainer; I'm never going to find those jobs for all those poor disabled people who want to work; I'm getting out of here."



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When Doctor doesn't know best



Why, asks **Penny Batchelor**, doesn't the NHS embrace the social model of disability and empower us to help them by making our own informed decisions

It started with a rather unattractive and large bird poo on my car. I needed to fill up with petrol and instead of going to the pay-at-pump petrol station I would normally go to for ease of use, I went to a different one that had a car wash.

When I walked to the kiosk to pay I came a cropper, slipping on a manhole cover and fracturing my femur. As I was born with brittle bones, fractures come with the territory. This also means that I have infinitely more experience in dealing with them than the average, well-meaning NHS employee.

I couldn't fault my care from the ambulance and A&E staff and was very grateful for it. But why does "the system" insist on following the medical model of disability and not the social model?

To "the system" I was a conundrum. I fell in London, where I had been visiting a friend. I live in the Midlands, but had to go back to stay

with my parents in Yorkshire for a fortnight until I was mobile enough in a wheelchair to go back home.

There came the rub. I didn't have a wheelchair. When the London hospital discharged me they wouldn't lend me a wheelchair. If I refused to leave without one I'd have to be admitted, taking up a bed that could be used for someone else. Up in Yorkshire, my parents' GP surgery told me I could register as an emergency

Why does "the system" insist on following the medical model of disability and not the social model?

patient but it would still take at least a week to be assessed for some wheels. My own GP was very helpful but I needed to be back home to be assessed by own county's team – and to be back home I needed a wheelchair to be able to



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do something as basic as get to the loo unaided. In the meantime, like a scene from a comedy film, my mum inventively used their study chair on castors to wheel me from room to room.

The catch-22 situation was only broken when, after lots of phone calls, my dad managed to hire me a wheelchair. Of course not all of us can go to the bank of mum and dad for

a temporary solution whilst "the system" follows its rules.

Clearly, NHS resources have to be applied efficiently and fairly. However, more listening to disabled people, who through our experiences become the experts on what we need, would save not only time and resources but tear down some of the unnecessary barriers we face every day.

→ Have your say

- write to us **Disability Now**, 6 Market Road, London N7 9PW
- email us editor@disabilitynow.org.uk
- phone us 020 7619 7323

upclose&personal

Adopting a position

With more than 40 years in the adoption business and having been brought up in care herself, **Carol Howard** is well placed to see how the system can let down disabled children

When I'm out with my four sons, with two (sometimes three) of them using wheelchairs and two of them white and two mixed race, it's clear we aren't the average family. People guess that the kids are adopted and say, "Oh, you're doing a great job, but I suppose you get a lot of help". No! I don't!

I learned long ago about the difficulties of accessing goods and services for disabled children. Adoption agencies lead you to believe that if you adopt a disabled child you will get a package of care and financial support but I've had to fight many battles to get my boys what they need.

Three of our children are disabled as a result of child abuse when they were babies. I get very angry about the thousands being spent on the inquiries into the mismanagement of the Baby P case - when if he had lived and been disabled from his injuries - he wouldn't be deemed worth the resources.



THE DEVON HERALD EXPRESS

My son Conor was abused by a foster carer and his head injuries weren't discovered for two months. By the time he started school it was clear that he had learning difficulties, but he's now ten and he still doesn't have access to an appropriate form of education. The specialist help he needs costs £5,000 per year and an independent tribunal ruled this cost

"unreasonable additional public expenditure".

It's such a blinkered, short sighted attitude. Conor was so frustrated with not being able to read and write that he felt suicidal. He's already 50 months behind his peers. If he isn't adequately and appropriately educated he will become a statistic. A high proportion of prisoners have been in the care system or have learning

difficulties. Conor needs access to education to equip him for an independent life.

The professionals say, "The most important person in the child's life is the parent; they know the child best". That only holds water until you disagree with them and challenge them. If I say, "that style of wheelchair won't fit in my car", if I have an opinion, all of a sudden they know best and I'm marginalised. It doesn't matter if you have a good track record and are meeting milestones and have been right before.

I'm answerable to a lot of people but nobody is answerable to my children. In all this time no one has ever sat down with Conor and asked: "What do you want?"

I'm passionate about adoption: I'm hooked. But it's not enough to issue a disabled child with an adequate mummy and daddy: you need support and resources.

I was in care myself, so you don't have to be a psychologist. I had a good experience but it's not an ideal way to get parented. The system doesn't do much positive for any children, so it does very little for disabled children and a disproportionate number of them are staying in the system.

• Carol Howard was talking to Kelly Mullan



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The first Clothes Show London (CSL) promised to be a three-day style and fashion feast. With ticket prices at £24 a day and even more to attend the "prestigious award ceremonies" (celebrating the year's best beauty products, best dressed woman etc), I was keen to find out exactly how much bang I was going to get for my buck. And at that price, I was expecting fashion dynamite.

CSL, held at ExCel in London's Docklands, provided everyone with free parking for the event and access was faultless; I rolled straight from the car into the enormous exhibition centre and there were lifts and accessible loos throughout.

Arriving in the first hall, I was confronted by a large fake beach with a life-sized sand sculpture of a horse lying down and a voluptuous nude woman resting her generous breasts on its back. How did this creation relate to fashion, I wondered. Was this some naturist-influenced alternative to the Wonderbra? My ponderings were short-lived as a gang of scantily clad models, including some very gorgeous young guys, burst from the beach hut showcasing the latest Figleaves swimwear collection to a startled but smiling smattering of passers-by.

Moments later, an excited gaggle of girls and photographers alerted me to the appearance of Katie Price who was signing her "equestrian range" (www.KPEquestrian.com) featuring such horse-riding essentials as pink velour hot pants. I obviously wasn't in the market for riding clothes but thought a photo of me and KP would complement my article. However, Katie's massive minder got a whiff of my press pass and gruffly

All eyes and teeth – how **Lara Masters'** partial make-over failed to impress Katie Price's minder



JO BALL

Lara's clothes show close-up

informed me that Miss Price did not want to meet me. "But you haven't asked her if...?" I pointed out. He glared at me and boomed: "She doesn't want to meet you!"

Practically in tears, I sped away almost landing in a barrel of glitter eye-shadows. I let a make-up artist restore my serenity with a few

sweeps of sparkling lapis blue as she explained that "B", or "Never Too Busy to be Beautiful" (www.bnevertobusyto be beautiful.com), are the only UK cosmetics company whose products are entirely vegan and against animal testing.

With sparkingly ethical eyes, I



I was confronted by a large fake beach with a life-sized sand sculpture of a horse lying down and a voluptuous nude woman resting her generous breasts on its back

started my reconnaissance of the clothes stalls which were mainly independent labels with refreshingly few recognisable brands. In the Untold London Boutique, 11 emerging designers and artists were selling their ranges but I found these clothes to be unspectacular with lots of boxy, frumpy shapes. Checking out some of the more commercial clothes stalls was also disappointing with many mass produced, poor quality badly cut garments and a theme of fraying hems, ugly prints and fabrics that looked and felt cheap.

At least in Anita's Vintage Fashion Fair the clothes were a higher standard of craftsmanship but with retro stores it's always a question of luck that you find something that fits or can be easily altered, but I didn't find anything enticing even in the handbag, jewellery and hat sections.

The one beacon of light in an otherwise murky clothes abyss was a stall full of hand-made corsets and retro-style dresses in stunningly vivid prints by a label called, wait for it... "Limb"! (www.limb-clothing.com)! Did they see this *DN* journo coming or what?! The corset I wanted was too long to wear sitting in a wheelchair so the owner said she would make me a shorter version at no extra cost! I didn't even have to mention the DDA or anything!

This last minute goal put a smile on my face which was promptly enhanced by a woman leaping from her stall and smearing teething whitener over my gnashers, instantly making them two shades lighter. Apparently.

Teeth-glinting, I moseyed past the Style Stage where a celebrity hairdresser was effusing about this season's hair-dos and don'ts, and on to the Fashion Theatre with its designated VIP/disabled area, to catch the end of Katie Price's catwalk show. Afterwards, I manoeuvred my way backstage and past an army of security guards and KP's now quite sleepy bodyguard by flashing my press pass and fluttering my ultra-sparkly eyelids. I ended up hanging

out with beautiful male model Max and Miss Price as we bonded, comparing waist sizes and choosing her outfit for the evening.

To summarise, with over 90 stalls of beauty, style and fashion retailers, and related businesses such as photographic and model agencies and fashion and beauty colleges, it occurred to me that the Clothes Show London is perhaps a misleading

Katie's massive minder got a whiff of my press pass and gruffly informed me that Miss Price did not want to meet me. "But you haven't asked her if...?" I pointed out. He glared at me and boomed: "She doesn't want to meet you!"

title. Sipping on my fourth free Martini Rosato (everyone got given two and I responsibly relieved my carer of hers), I concluded CSL is more a style Mecca, where you can get expert advice and an education in all image-related industries, than simply a place to clothes shop. ■



Travels with my daughter

Elephants, camels, horses and zip wires. Seasoned independent traveller **Nicola Naylor** rediscovers the deserts and forts of Rajasthan in the company of her nine-year-old daughter

I had been waiting for my daughter to be old enough for a holiday in India. At Easter, she turned nine and we were off to visit Rajasthan where we spent three glorious weeks, and I discovered that touring with Poppy added another spectrum to my view of travel. I had visited Asia many

times but until this trip had only seen and written from the perspective of a blind woman travelling alone.

Old enough? A difficult one to answer. Old enough to be my guide? To be helpful at times would be a bonus, but to shoulder the responsibility of guiding in such a foreign environment

would, I felt, be too great a burden for some years to come. I wanted her to be mature enough to absorb the culture shock and to experience and enjoy the vastly different way of life with all its colour and vibrancy.

I hoped Poppy would love India as I do, but I also wanted to bring her and her belongings home safe and sound. There is some irony that as a blind mother I managed to produce the most extraordinarily independent child who developed a propensity for wandering off as soon as she could walk. Poppy is now able to curb her explorer's zeal some of the time, especially when faced with the commotion and thronging crowds in an Indian street. I also felt that Poppy was now less likely to leave her backpack somewhere, or open for someone to pilfer the contents. This is important when you can't just glance over and quickly check for them.

The trip still needed to be tailored to



Clockwise from far left: Poppy riding a Marwari horse in Narlai; Camel safari at Reggie's camp in Osian; Poppy and Nicola visiting the beautiful Fort Seengh Sagar; Poppy and Nicola in a cycle rickshaw in Old Delhi; Poppy and Nicola walking through the streets

appeal to a child. I soon realised, to my pleasure, that this coincided beautifully with my own preferred way of travel, which is through experience and activity. If you are blind, there is no point in touring, cooped up in an air conditioned vehicle behind glass, and sight seeing is of limited interest. Too much of this would also have induced wails of protest from Poppy. One happy solution was to book lots of elephant, camel and horse safaris as a way of exploring the countryside and desert.

When we arrived at the Dera Amer elephant farm, near the famous Amer fort, there was a row of seven enormous elephants lined up to greet us, each with a Mahout, the elephant's own trainer, perched on top. There were two waiters, one with cold towels for us to mop our brows and the other with a tray of bananas for us to feed the elephants.

The velvet feel of the trunk gently and nimbly folding round the banana was very reassuring. We soon got used to lolloping through the Aravalli foothills with the occasional deep vibrating purr from our elephant and the sounds of gathering dusk. It was easy to imagine ourselves as Maharajas on a trek to a royal residence. There was a cold beer stop and a camp fire dinner at nightfall with musicians and dancers. It was all hosted by Udaijit Singh, a conscientious, Rajput landowner who has diversified but maintained local tradition. The only complication was getting on. We mounted from a tall

Did you know?

Rajasthan is the largest state in India by area and is 40 per cent bigger than the UK.

tower and my problem was discerning the back from the front of the cushioned chair we were to sit in. Poppy hooted with merciless laughter and offered the, for me, useless information that the back was where the tail was.

We rode camels at Reggie Singh's desert camp in Osian in the Thar desert where we stayed in a luxury tent with an ensuite modern bathroom, and a swimming pool built on top of a sand dune. This time I was prepared to mount as the camels were kneeling on all fours and there was just the forward, backward swing up. The silence of the desert and the thud of the camel's feet on the sand were hypnotic. On camelback, we were able to reach many remote desert villages where we were welcomed into dung huts with straw roofs for chai 'tea'.

Apart from finding that being





Top two pictures: Zipping with Flying Fox at Neemrana. Bottom two: Meeting the elephants at Dera Amer



mounted in the open was the most enjoyable way to soak up the atmosphere and get to know the countryside for both of us, it was also fascinating to be in such close contact with animals that we would not normally meet. The tough feel of the elephant's skin and the camel's hair was amazing. The Marwari horses have lyre-shaped ears which point inwards and almost touch at their tips. These ancient horses of the Marwar region were also interesting to ride. They prance and carry their heads so high that they wear colourful, cloth martingales to stop them bashing their riders' noses. Rohet Garh, a former home of nobility is the heritage hotel with the finest collection of horses, but both Rawla Narlai, a former shooting lodge, and Deogarh Mahal offer fabulous trekking. We covered much more terrain on horseback. My only concern was whether I would be told about overhanging branches as the others were busy spotting wildlife like the blue bull and the black buck.

It was the beautifully restored heritage properties converted to hotels that made our decision not to do too much sightseeing an easy one. We didn't miss out by not seeing many city palaces and

forts because we experienced them first hand by staying in smaller versions. We could soak up the history at our leisure. Deogarh Mahal is a sumptuous palace, over 300 years old, owned and restored by the Rawat Nahar Singh and his family who live nearby and visit their guests most evenings. Poppy was thrilled to take tea with a real, and delightful, King and Queen and to be invited to a lakeside picnic, a torch-lit dinner in one of their forts and a visit to their summer palace, deep in the desert and on the banks of a (currently dry) lake, which is now for hire to private parties. We enjoyed the opulent royal suite complete with what seemed like an opium den with mirrored walls and coloured glass baubles, reflecting the gaudy decadent taste of bygone royalty. Poppy explored the many rooftops and inner courtyards of the palace while I

decided that the audio guide, prepared by William Dalrymple, was one of the best of the many that the heritage hotels had to offer. This is also the only one with a lift installed.

Neemrana fort, built from 1464, is perched high on the Aravalli range between Delhi and Jaipur and is also steeped in history with its ramparts, keeps and endless corridors and steep stairways. Here, I had my first experience of zipping, organised by Flying Fox who have built India's first zip course. It is made of steel cables suspended high above the craggy mountain tops and the fort's battlements. You are attached by a harness that you wear and accompanied by members of a professional team of experts. The sensation was like flying! Poppy was too young to join us on the zip wires as you have to be over ten. She watched, a little crossly, from the battlements. I don't think it is such a bad thing for youngsters to see parents do something they can't yet do themselves, especially when one is disabled.

The environment could be challenging for both Poppy and me at different times. She was made uneasy by people staring at her and needed some reassurance. I, on the other hand,

Did you know?

Marwari horses almost became extinct after the Second World War and their export was banned until 2000. Since then some have been sent to the USA and Europe. One is currently on its way to the UK as a gift from Rohet Garh.

needed a hand, particularly in some of the older properties, descending their steep, uneven steps. Poppy found these convoluted buildings so irresistible to explore and often ran on ahead, setting herself the challenge of finding her own way. At these moments she wanted to think that a small thing like a precipice of steps was of little consequence to her intrepid mother. However, she was always at her most attentive when we were out, and she wanted to steer us both clear of dirt. She hated the pollution, made worse by heat and dust, and the filthy, rubbish filled streets. Her reaction also made me much more aware of the dirt than I had been previously. I also became more convinced that children can be willing and excellent guides, but it needs to be on their terms until greater age makes them less easily



Poppy exploring the palace rooftops at Deogarh Mahal

distracted and more empathetic.

There was the added advantage on this trip of enjoying my daughter's view of what she saw. Although I do enjoy assembling my own picture, I liked seeing things through another pair of eyes. This was not merely having things described to me, it was often just gauging the honest reactions of a child to what she saw. I always knew how close we were to having a near-miss with a cart, careering with no brakes, or with a cycle rickshaw, skidding out of the way of a water buffalo, by how hard Poppy gripped my wrist! I felt her fear and her fascination which gave me a fresh take on the India I

thought I knew so well. I think we have returned having truly shared a fabulous experience and a new love for India. ■


Tips

Return flights From London to Delhi from £350.

Best way to travel within Rajasthan is by hiring a car and driver at a cost of around £50 all-in, per day. Cheaper alternatives are trains and buses.


The heritage properties offer a wide range of prices but a double room is between £60-£100 per night.

Emma Horne of Nexstop is a private travel adviser living in Delhi and can organise and personalise trips.
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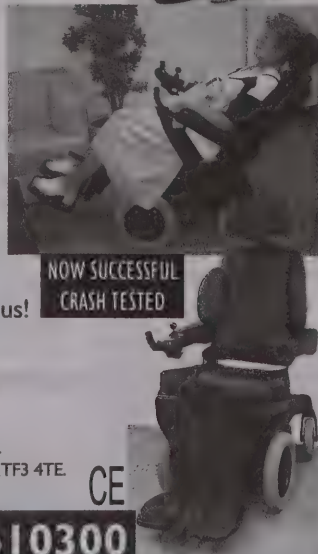
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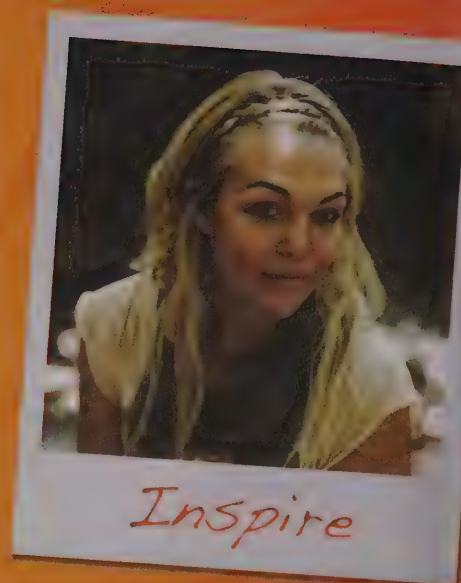
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Something missing in Life

While his eight-year-old son revelled in a family day out at the Life exhibition centre in Newcastle, **Ian Macrae** came away ultimately disappointed by what it left out



CENTRE FOR LIFE

The former industrial hinterland behind and around Newcastle's Central Station has, like much of the rest of the city, been transformed. Spaces which were once tramped by railway and other workers in heavy industry, are now thronged with the city's bright young things by night and tourists by day.

Among the bars and restaurants which make Times Square a hub for nightlife is a permanent exhibition of life on a much broader scale.

The Centre For Life is part of Newcastle University, a serious scientific enterprise devoted to the study of genetics, embryology and other areas of the very stuff of life itself. Associated with this – representing perhaps, as it were it's public, more easily understood face – is



Life, a permanent exhibition reflecting human life on earth in all, well almost all, its diversity.

In one scary corner there's an LED display, counting into the billions and ticking over at an alarming rate as it records the birth somewhere on the planet of each new human baby. Elsewhere you can explore how greedily cities consume precious resources like water and energy. Other parts of the permanent display are given over to the body and how it works.

It would be easy to say that the fact that there don't appear to be any exhibits which represent the richness and sheer difference of disabled people's lives reflects the exhibition's association with its academic alter-ego across the square, concerned as it partly is with screening for hereditary conditions and impairments, but this lack was a major disappointment to me. After all, disability is a fact and fully a part of human life. And given that the exhibits are aimed at children like my eight-year-old who embraced the whole thing with total enthusiasm, you'd have to say that this represents an educational trick missed.

My boy's enthusiasm was equally engaged by a small collection of roaring, spitting and chomping anamorphic dinosaurs, a special display timed to coincide with the school half term.

Other attractions include a simulator which creates the impression of a white-knuckle ride complete with 3D visuals and pitching seats. This too was tied in with the dinosaur theme. It's open to any disabled people who can transfer from a wheelchair.

Wheelchair spaces are also available in The Dome, a cinema with the screen set like an enormous dome into the ceiling which shows a short programme twice every hour. Mobility impaired people might want to note that queuing times for this grow when the centre is busy.

It's clear that access has been central to the thinking in how the exhibition was put together – although there was a surprising lack of audio support for many of the more visual displays. It also seems likely that this is primarily a kids' day out, and it's therefore a disappointment that they're not given the chance to share in aspects of life beyond the merely normal.

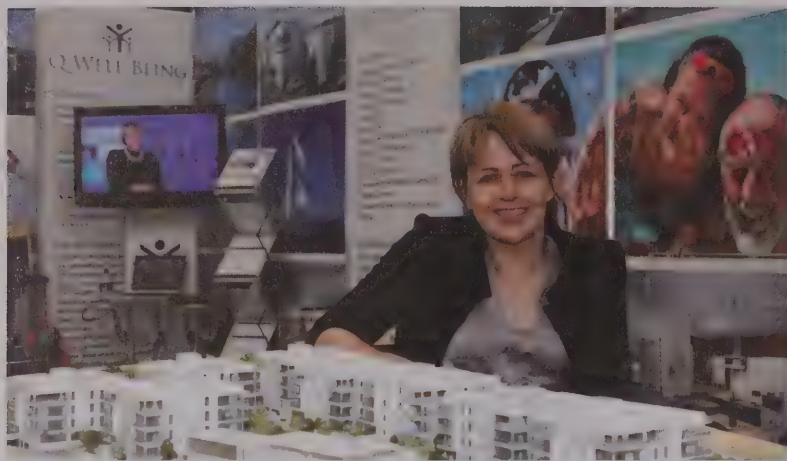
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www.life.org.uk

roadtest



Hybrid and highlights from Mobility Roadshow



For 25 years the Mobility Roadshow has been growing its reputation as the best place to see what's new in getting around for disabled people. **Douglas Campbell** checked out this year's exhibits

The worrying state of the economy was obvious with some long standing exhibitors not attending. Vauxhall, Gowrings Mobility and Portaramp have all had significant stands for many years, but they all chose not to be there.

In pride of place as you entered the Honda stand was their environmentally friendly Insight. This petrol and electric hybrid car uses an electric motor and batteries to substantially reduce emissions in slow traffic and completely when stationary. The interior of the four door hatchback is very

spacious and the batteries have been cleverly located so that they do not take up luggage space. The batteries are charged by the petrol engine and from the energy created when braking. The automatic continuously variable transmission makes for easy driving, although the many dials, gauges and buttons in the cockpit display may seem a little daunting at first.

The Insight is surprisingly competitive with a Motability contract hire advance rental of £2,974, which is almost the same as the Toyota Prius. The list price starts at £15,490, but you could get

£2,000 off by trading in a car registered before September 1999 under the Government sponsored scrappage scheme and perhaps even a discount too.

Unfortunately, the reality is that buying the greenest technology can be expensive and the savings in fuel costs will not be adequate unless you do a very high mileage. Remember though that all modern cars are much more environmentally friendly than their older equivalents and the scrappage scheme is available for most makes of car when purchased new.

Steering Developments were showing their new

wheelchair loading robot, the Abi-Loader. After the driver has transferred from wheelchair to driving seat this manipulator takes the wheelchair from beside the driver round to the back of the car, stows it in the boot and shuts the tailgate. At the end of the journey the whole process is easily reversed. The vehicle has to be suitable with regard to the boot and tailgate design, but many makes and models will fit the bill. Unlike automatic roof boxes this system does not change the shape of the vehicle and avoids the resulting substantial increase in drag and fuel consumption. Priced at £5,985 including fitting this is not a low cost solution, but it may make all the difference if you can transfer from your wheelchair, but not load the wheelchair unaided.

The Highways Agency has responsibility for the trunk roads and motorways in nearly all of England. As

part of their service they launched at the Roadshow a magazine for disabled people with information on:

- What to do if you breakdown
- How to avoid breakdown in the first place
- Journey planning
- General road safety tips

The Roadshow also featured holiday and travel opportunities. Particularly noticeable was the model of the luxury five star accessible holiday homes in a unique development on the outskirts of Larnaca, Cyprus, that are to be completed in 2012 by Q Well Being. An

expert team of designers have come together to ensure every little detail has been thought about. The team include Dame Tanni Grey-Thompson DBE, Paralympian gold medallist, Dr. David Bonnett RIBA, FRSA, access consultant for the Olympic Athletes Village in Stratford City, London and Adam Thomas, the UK's only disabled specialist accessible kitchen designer. Tanni showed us the model and told *Disability Now*: "Now I'm retired from competitive sport, I still want my family to have somewhere we can

all relax comfortably and safely together".

The access and design look superb and with flats of various sizes and the ability to meet individual needs they are bound to prove popular. Currently flats are for sale and can be bought by groups of up to four people. It is very likely that some owners will rent out the flats to holidaymakers.

There was lots of fun too. Skid cars screaming sideways across the tarmac. A chance to experience flying in a small plane. Even a temporary climbing wall.

INFORMATION

Honda:
www.honda.co.uk;
 0845 200 8000

Motability: www.motabilitycarscheme.co.uk;
 0845 456 4566

Steering Developments:
www.steeringdevelopments.co.uk; 01442 212918

Highways Agency:
www.highways.gov.uk/disability; 08457 504030

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www.qwellbeing.com;
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Paralympic World Cup: British cyclists set records...



ACTION IMAGES / JASON CAIRNDUFF

Great Britain's superior dominance in Paralympic cycling was put on show once again with a superb team performance at the Paralympic World Cup in Manchester.

The British cyclists picked up where they left off from the Paralympic Games in Beijing by winning ten gold medals and setting two new world records.

Jody Cundy (*photo, above*) in particular shone for Great

Britain, with the former swimmer sharpening his reputation as a world class cyclist in his own right.

Cundy took gold in the LC1/LC2/CP4 1km time trial, before smashing the world record in the 200m time trial with a lap of just 10.998 seconds.

He also claimed gold in the team sprint with fellow Brits Darren Kenny and Mark Bristow.

Cundy said, "To have had

the opportunity to break the record here in Manchester at the BT Paralympic World Cup, on a home track in front of a home crowd with friends and family, is great."

Kenny was also on hot form as he added double Paralympic World Cup gold to the four golds and one silver that he won at last summer's Paralympics.

He led fellow countrymen Rik Waddon and Simon Richardson home in a British one-two-three in the 1km time trial for LC3/LC4/CP3, before seeing Japanese cyclist Ishii Masahi off in the CP3 3km pursuit final.

"I'm pleased with my performance: it's all gone pretty much to plan," he said.

"I've not done a lot of specific track work ahead of the competition but I knew I'd perform, just maybe not as well as I actually achieved today – so it's good."

There were also golds in the Blind/Visually Impaired 1km time trial from Aileen McGlynn and Vicky Blegg.

Meanwhile in the men's event, former Paralympic judo star Simon Jackson and pilot Barney Storey edged out newcomers Neil Fachie and David Readle in a time of 1:04.029.

Jackson said: "It feels fantastic to win the world

title here. I left my job in January to go full-time and commit myself to another sport after retiring from judo in 2005, and the rewards are now there to see.

"I train here every day in Manchester and all the other Paralympians that I train with have got gold medals.

"I've always felt a bit left out so it feels good now to have that gold medal draped around my neck."

Another former swimmer, Sarah Storey, also got in on the act, winning gold in the women's 500m LC1/L2/CP4 time trial before storming to an emphatic victory in the Women's 3km Pursuit with an impressive time of 3:46.403.

There was also some controversy at the event as Paralympic champion Anthony Kappes took to the track with former Olympic cyclist Jason Queally as his pilot.

The kilo race was billed as an "exhibition event alongside the Paralympic World Cup", as Queally is not yet eligible to compete in Paralympic cycling.

(Former elite athletes have to complete three years away from non-disabled competition before being eligible to take part in Paralympic sport.)



David Weir storms to victory in the 1500m

ACTION IMAGES / CRAIG BROUGH

...while British athletes strike gold

Great Britain's athletes picked up four golds at the Paralympic World Cup in a glorious day under the sunshine at Manchester's Regional Athletics Arena.

Wheelchair racer David Weir led the way for GB, first taking silver in the T54 800m behind Switzerland's Marcel Hug, before reversing the positions to power home in the 1500m.

"It feels good to win two medals and get the cobwebs out after Beijing. I've had five months out so I'm pretty pleased with my performance", said Weir.

Ben Rushgrove, who two

years ago smashed the world record in the T36 200m, set a championship record in the same stadium on his way to gold in the 100m.

"I'm a bit disappointed with the time if I'm honest. It was a good run but it could have been a better run", he said.

"Every time I go out I just try to push the boundaries a little bit further", he added.

Elsewhere on the track, Paralympic silver medallist Libby Clegg won gold in the women's T12 100m, but was unable to repeat the performance in the 200m, finishing with a bronze.

On the field, Daniel West won gold in the F54-57 shot put.

Despite the strong British contingent, the man whom most had come to see was South African sprinter Oscar Pistorius.

Competing in his first races since a serious boating accident in February, Pistorius showed signs of rustiness. In the T44 100m, he had to produce a blistering final 20m to snatch victory on the line from rival and rising US star Jerome Singleton by three hundredths of a second.

Things were more straight-

forward in the 400m, his preferred event, though his time of 50.28 was way outside his personal best of 46.25.

"The 100m was always going to be a tight race and it was always going to be a matter of catch-up because Jerome Singleton is very fast in the first 30m," he said.

"My time in the 400m was shocking – it was the worst time I've run in about three and a half years, but I know I wasn't running hard and can run a lot better."

Despite the positives of the event, the day ended on a sad note for former Paralympic champion and world record holder Danny Crates, who pulled a hamstring in the T46 800m, his first international appearance since having to withdraw from Beijing through injury.

It was the latest in a line of injury problems and setbacks for Crates, who earlier this year had his funding cut and then partially restored by UK Athletics, just two months after being given the honour of being Great Britain's flag-bearer in Beijing.

The 36-year-old insisted that despite the injury, he would not be forced into retirement and would continue to try and prove his fitness.



Simmonds, 14, is No. 1



ACTION IMAGES / JASON CAIRNDUFF

Teenage Paralympic star Eleanor Simmonds was the star of the show again at the BT Paralympic World Cup in Manchester as she smashed the world record in the S6 100m freestyle.

The 14-year-old broke the previous record of 1:17.43 with a time of 1:16.21, ahead of fellow Brit Natalie Jones in second.

She was surprised, she said. "I didn't think I could get a world record in the 100m. It's not even my favourite – the 400m free is – so to break the world record in my second

event with two seconds off my PB is really good!"

GB took 18 medals – nine of them golds – in the pool at the Manchester Aquatics Centre, continuing last summer's success in Beijing.

Also among the golds was Paralympic multi-medallist Dave Roberts, who in the S7 50m and 100m freestyle went head to head again with teammate and rival Matt Walker. In the 50m freestyle, Walker looked like claiming a rare victory over Roberts but the Welshman stormed back to snatch the win by

0.16 of a second.

In the 100m, Roberts had things more his own way, leading from the off to take gold ahead of the USA's Lantz Lamback, with Walker back in third.

"That was sweet", Roberts said. "Neither swim was that good but sometimes the winning's more important. Back-to-back racing is hard work and I broke the world record in the 400m yesterday, so that doesn't help."

Referring to the close race between him and Walker, he added: "I expected to win

the 100m but Matt beat me in the 50m at the European trials. It's an open thing: he beat me last weekend and I beat him this week."

There was a British clean sweep in the S9 50m freestyle, with Louise Watkin touching home first in 29.41 ahead of Stephanie Milward and Lauren Steadman, while in the S8 100m backstroke, Heather Frederiksen narrowly missed beating her own world record on the way to claiming gold.

Also in action was South African swimming powerhouse Natalie Du Toit, who saw off the opposition in the women's multi-disability 100m freestyle.

Du Toit, who last year became the first female amputee swimmer ever to qualify for the Olympics, held off Watkin by just over a second to win gold in 1:02.42.

Shooting up: GB scores bronze

A new-look GB men's wheelchair basketball team had to be content with bronze at this year's Paralympic World Cup, as favourites Australia stormed to gold.

With several of the bronze-winners in Beijing having since retired, it was a relatively inexperienced side that took the court.

That inexperience showed at the start of the contest, with defeats against the USA,

Australia and Germany in their opening three matches before going down to the Australians again in the semi-finals. But a much-improved performance in the bronze medal match saw GB claim third place with an impressive 69-49 victory against Germany.

Top scorer Joe Bestwick said that it would take time for the new team to develop.



ACTION IMAGES / MICHAEL BEGAN



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ORTHOPAEDIC

Shaping up to 2012

The Cultural Olympiad may be all well and good, but, asks **Kelly Mullan**, do disability arts and sport make comfortable bedfellows



Shape Arts has commissioned two disabled artists and two disabled-led companies to develop work that responds to the themes of the Cultural Olympiad. The artists' new humorous, sometimes cynical, works are being showcased this summer at London's Southbank.

The spirit of fun imbuing the Shape artist commissions has been apparent since the launch event last year when a panel of giggling artists revealed their puzzlement at sport. Deaf artist Aaron Williamson asked why all

the Deaf athletes don't just win everything at the Paralympics, and Shape's Tony Heaton quipped that it's because they don't hear the starting gun.

After such an auspicious start the resulting art work has been hotly anticipated. One thousand people saw the first three Showcases on a sunny bank holiday Monday. There was plenty to see for both children and their chin-stroking cultured parents.

Running with scissors as an Olympic sport may not catch on, but Kazzum Theatre Company rolled up to Southbank with a mobile newspaper stand and got

watching kids to help use Chinese paper cutting to tell the smaller tales within the big Olympic story.

As the diversely proportioned dancers of Stop Gap Theatre Company took to the stage, a mother in the audience shouted at her child: "How would you like it if you had no legs?" Challenges to perceptions of disability were overheard and boxes were ticked.

Stop Gap's *Tracking* is all thundering beats, high energy street dance and cool costumes. Looking at Britishness and identity, Stop Gap use 70's kitsch, hide like spies under umbrellas, queue

(energetically), and host their own Games.

Inside, away from the family fun in the sun, Aaron Williamson's film, *100 Metres Gold Handicap* (*King Midas*) was showing to a gaggle of more serious looking viewers pondering the joke as comment. In *King Midas*, the mythical Greek figure is attempting the 100 metres. He should be the perfect Olympian as everything he touches turns to gold but he has turned himself to gold and is heavily handicapped.

The strange bedfellows of sport and art are producing some quirky and entertaining offspring. Seb Coe has blessed the union saying: "Our Cultural Olympiad will widen the experience of 2012 beyond sports participation. It will enable those with talents in other areas to share the magic of having the Olympic and Paralympic Games in their own country." We certainly won't be the first wedding guests to take bets on how long it will last whilst still enjoying the party.

The next Showcase will be on 13 July when sit-down comedian Liz Bentley unveils her wares, and the artists will be on the festival circuit throughout the summer.

BOOK

**Important things said
in an unusual way**COACHING PEOPLE WITH
ASPERGER'S SYNDROME

Bill Goodyear



Coaching People with Asperger's Syndrome (Karnac, £20.99) is a specialist book disguised as a general manual by an author who has taught autistics all his life. Regrettably, there are no pictures and the book is sometimes patronising and confusing but it can be helpful in other ways. Page 21 highlights a pitfall for many AS university students: "Some fail to make it through to the third year, torpedoed by the lack of structure." Here, coaching

can make a big difference.

In some places the book contradicts itself. Page 203 says, rightly, "avoid paraphrasing; use identical language", because AS people find it hard to process language. But Tip 39 reads: "Say important things several times in different ways if you want them to be remembered."

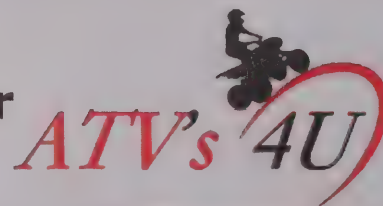
The best advice comes on page 121. The author had a pupil with 32 challenging behaviours. He ignored all but the mildest (repeatedly

tying shoelaces) and after six weeks they'd all gone. He also says that families shouldn't collude with AS children because it disempowers them.

On the other hand, the author's New Ageism leads to some incredible remarks. He says meditation is "the single most important thing for you and the other person to learn." Bizarre, too, is his admiration of Franz Mesmer, who was "definitely on to something." Needs editing.

Edmund West

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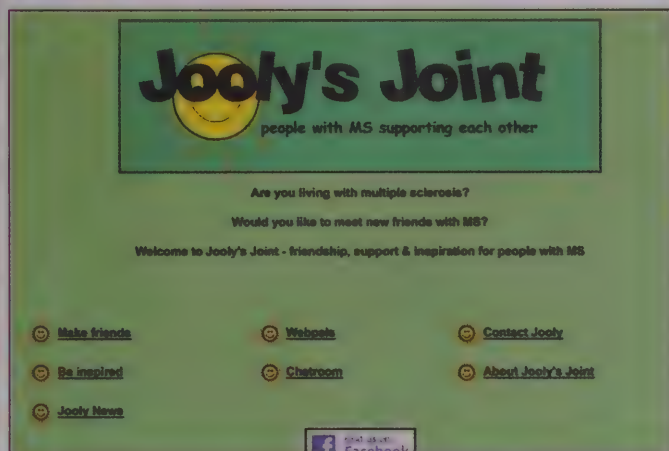
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webwatch

In on the ground floor



In the early 90s, when the web was still the "Information super highway", **Julie Howell** was one of the first to travel on it



I like to think of myself as one of the web's pioneers, an early disabled adopter. I first got online in 1995, before most people knew what "online" was. Within months I'd set up one of the first online communities for people with multiple sclerosis (www.mswebpals.org).

The web is now a fact of life for me and, like running water and electricity, it's an essential resource that I take for granted.

There are a handful of sites that I wouldn't want to live without, that have become a group of trusted friends to whom I turn when I need advice or just want to

know "what's happening".

The first is the BBC News site (news.bbc.co.uk). I must look at it more than 50 times a day from my PC and – when I'm on the move – my BlackBerry.

I was a relative latecomer to Facebook (www.facebook.com). But eventually the sheer number of friends using it persuaded me to try it out. Now I can't leave it alone. And I'm hopelessly addicted to Facebook Scrabble.

My other favourite sites indulge my passion for spending money. Ebay (www.ebay.co.uk) and Amazon (www.amazon.co.uk) have been part of my everyday life for more

than a decade now. But it's the Apple iTunes Store (www.itunes.com) and fan-to-fan ticket exchange SeatWave (www.seatwave.com) that have more recently stolen my heart.

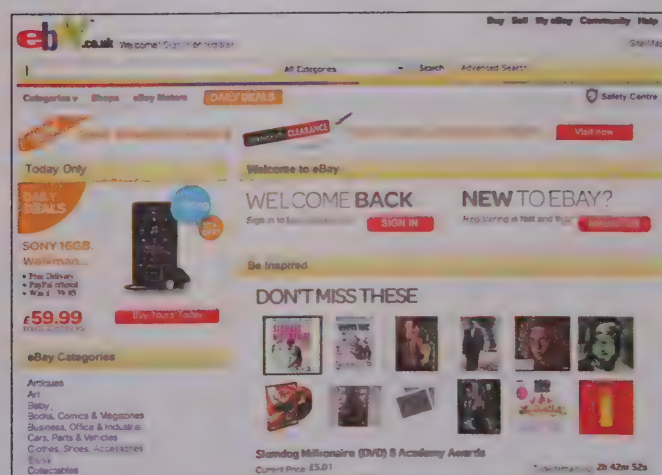
I know (because I've read it in these very pages) that some people are of the opinion that the web is "bad for disabled people" because too much time at home in front of the computer could lead to further isolation. I strongly disagree. For me the web has become a way for me to reconnect with my passions, and because of it I've never been so up-to-date with the news or what's happening in the lives of my friends. I definitely go out more since the web came along, because now I have

better access to information about travel and I feel more confident getting around on my own than I used to.

The web is a terrific channel through which we can make our voices heard, and where we're no longer constrained by geography but can move about freely and independently.

In my darkest moments I imagine life without the web and I don't want to be there. Let's keep the pressure on website owners to remember the needs of disabled people when they design their sites, because just as we have the most to gain, I suspect we now also have the most to lose.

• Julie Howell is director of accessibility at digital design agency Fortune Cookie.



→ Have your say

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- email us editor@disabilitynow.org.uk
- phone us 020 7619 7323

worklife

Happy feet

Because of the drug Thalidomide, **Sue Kent** says, she has only seven fingers and arms just eight inches long. Tired of being desk-bound, she looked to her feet to provide a working alternative

For about six years I'd been using my feet to give massages.

Then I decided to investigate massage as a career option.

To work in a clinic, I had to get a recognised professional qualification and show I could do everything that an able-bodied therapist could do, including head and face massage, with my feet.

Although the foot can't do what the thumb and forefinger can, healthy trained feet can be as sensitive as hands for the purpose of massage. The basic strokes don't need much dexterity of the toes, just flexibility in the hip, knees and ankles.

Generally I work from a centralised seated position and my clients – ranging from ten to 82-years-old, and split equally between the sexes – lie on a massage couch on the floor.

I've found I can give a powerful massage without much effort: this is popular with more muscular clients. I also have sensitive control of my toes, so that finer parts of the body like the

hands and face get equally successful attention.

Initially I worried there might be some resistance to offering body massage with feet. My solution for this was to do taster sessions at shows and found that any initial uncertainty was quickly replaced by interest and bookings.

Potential customers are occasionally put off when I explain that I have short arms, but most people are more open-minded.

I found little guidance for massage that uses the feet so I produced and now sell a DVD that covers the techniques I've developed.

The DVD gives a demonstration full-body massage



and illustrates foot exercises to develop flexibility in the toes, feet, legs and hips. I also demonstrate a full pedicure because soft, well-maintained feet are essential for massage.

I have strong abdominal and leg muscles because I've practised yoga all my life and have therefore found that working professionally as a massage therapist does not strain my body, but I do restrict my bookings to four hours of treatment a day. In addition, I give lectures and tutorials for disabled groups and massage therapists.

I'm keen to share my knowledge and experience, to encourage other people to consider using their feet for massage, but more importantly to urge them to be determined to follow up their career ideas, whatever the apparent obstacles.

• For more information, visit <http://www.enjoyfeet.co.uk>, email info@enjoyfeet.co.uk or telephone 01792 366938

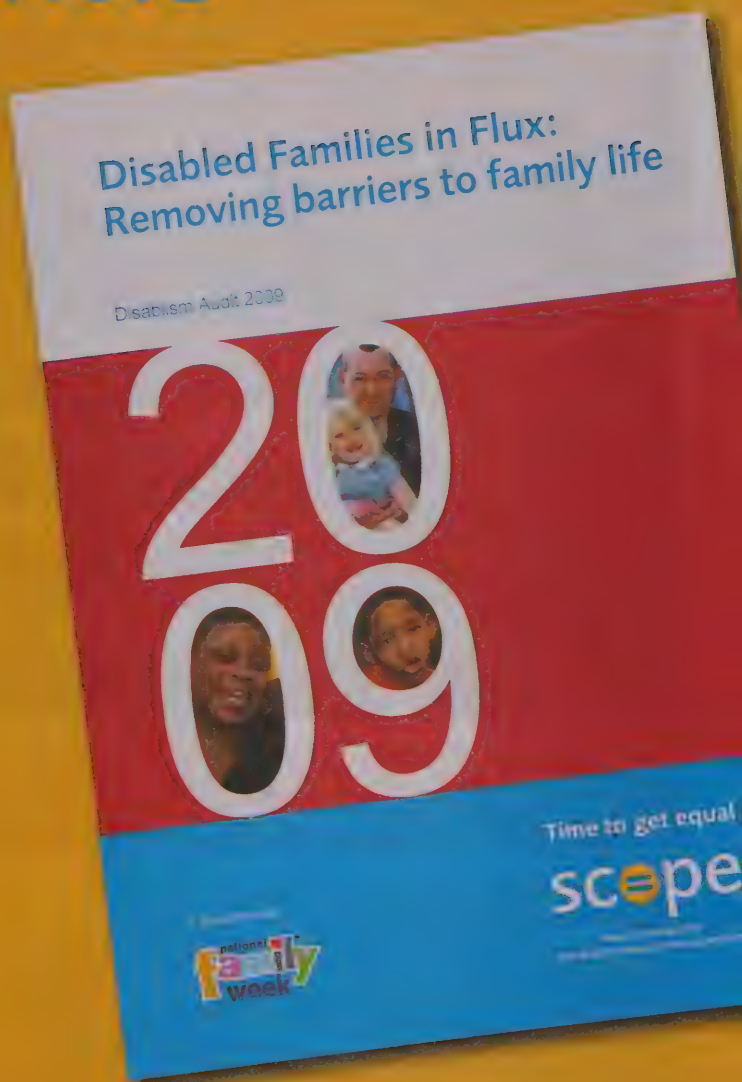
SUE KENT: CAREER PATH

- 1978-1980 – British Home Stores, office administration
- 1981-1983 – Bristol Polytechnic: HND Marketing and Advertising
- 1981-1983 – International Computers Ltd, Reading: full and part-time
- 1984-1987 – Argos Distributors Ltd, London Head Office, Buying and Marketing
- 1987-1988 – The Jewellers Guild Ltd, London Head Office, Marketing Executive
- 1988-2004 – Active Marketing / The Marketing Company: part-time
- 2000-2007 – Stephen Kent and Company, Chartered Accountants: part-time
- 2006 – Started Enjoyfeet Massage
- 2008 – Formed Enjoyfeet Ltd
- 2008 – Qualified as a professional massage therapist

Disabled Families in Flux: Removing barriers to family life

Families with disabled children are more than twice as likely as families with non-disabled children to have little or no quality time together according to a new report launched by Scope. The report goes on to explain the effect that isolation from local communities and lack of support has on many families' aspirations, quality of life and life opportunities.

The report, based on the voices of over 500 families, offers an insight into disabled family life and suggests a new approach to social policy. It focuses on how support services could be more sensitive to the needs of families by recognising the important contribution they make to society and better meeting their needs.



Disablism Audit 2009 now available

For full details and further findings from the report exploring the experiences of families with disabled children please visit:

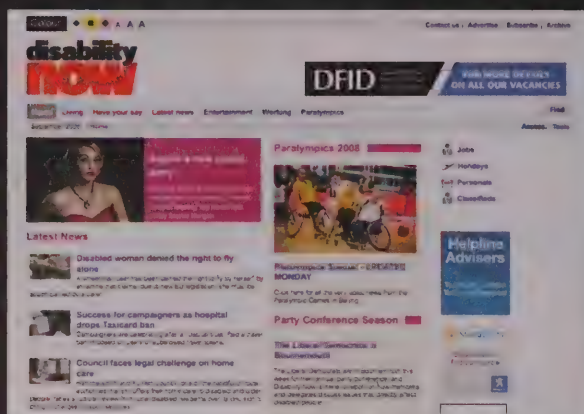
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backlash



Get Carter – on the run

Spiked, another great idea as **Paul Carter** learns his lesson about why he shouldn't run

I can remember quite clearly the last time I ran. It was 1999 and I was still a student. I can't recall exactly why I was running, though it can't have been for a lecture or anything like that. Maybe it was nearly closing time or something. Anyhow, what I do remember is the wave of emotions that spread across my brain quicker than swine flu – first surprise, then a fleeting sense of excitement which quickly melded into blind terror as I realised precisely what I was doing. I made a solemn vow after that brush with exercise that I would never run again. A vow I stuck to rigidly for ten whole years. Until recently.

In a peak of utter, utter insanity, and possibly mild drunkenness, I signed up to do a 2.5km run to raise money for Scope, which seemed like a good idea at the time. One of the major problems with this is my utter ineptitude at conceptualising distance. If anyone had told me that 2.5km actually equates to 1.55 miles (thanks Google) I would have had second thoughts. In actual fact I probably would have



third, fourth and fifth thoughts as well. However, after people very generously and graciously stumped up cash to sponsor me, largely I suspect out of Schadenfreude, I had to go through with it.

The biggest drawback with me running is that I'm not really built for it. My lil' legs don't much like it. Nor,

as I quickly discovered to my extreme discomfort, do my back, hips, arms and complete respiratory system. At one point I thought I was having a massive heart attack. After the first 100m it felt like I had already had a stroke. I'd also not banked on the residual suffering – nobody thought to mention the fact

that every sinew of my being would be aching for three successive days, causing me to hobble around the office like a geriatric, much to the amusement of the fellow occupants of *Disability Now* towers. It's true readers, I've actually found an activity that makes me MORE disabled.

What really surprised more than anything though was the sheer number of people who were out running on a Sunday morning purely for pleasure. What's wrong with these people? As of now, I'm starting a campaign to outlaw the use of the words "fun" and "run" in any sort of conjunction. The most enjoyable part of the whole experience for me was stopping running. The one upside to putting myself through such emotional and physical agony was the knowledge that I'd done my bit for charadee, which kind of made it worthwhile. Next time though, I suspect my fundraising efforts will be slightly more sedate, as I'm planning on leaving it another ten years before I run anywhere again. Ever. Sponsored sit anyone?

SCOPE




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people

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Directgov



www.direct.gov.uk/disability

Directgov is the website to visit for the latest information and services from government. It's clearly written, useful and the information is all in one place.

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- ➔ financial support
- ➔ disability rights
- ➔ employment
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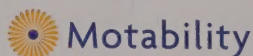
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